DOCUMENT RESUME

ED 181 709 EC 122 960

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TITLE Community Residences for Mentally Retarded People: A Study of Seven Community Residences.
INSTITUTION National Association for Retarded Citizens, Arlington, Tex.
PUB DATE May 75
NOTE 239p.; An abridged version of this document is available from Literature Sales Clerk, NARC 2709 Avenue E East, Arlington, TX 76011 ($1.75); Request: Community Residences for Mentally Retarded Persons: A Summary of a Study of Seven Community Residences. M.R. Research, No. 3, A monograph in the series published by The Research Advisory Committee

EDRS PRICE MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS Adults; Children; *Community Role; *Mentally Handicapped; *Normalization (Handicapped); Program Descriptions
IDENTIFIERS *Group Homes (Handicapped)

ABSTRACT

The report describes the distinctive characteristics and styles of seven community residences for retarded children or adults and provides a comparative analysis with emphasis on common themes of successful group homes. The homes are compared in terms of original initiation of the residence; the development of the residence; operations (such as philosophy, staff, and program); and costs and funding sources. Individual sections are organized into introduction, history and development, program, and observations for each of the following residences: Manchester Group Home (Connecticut), Lupine House (California), The Hearth (Pennsylvania), Cheyenne Village (Colorado), the Community Living Project (California), the Lori Knapp Home (Wisconsin), and the Hamilton Street Residence for Children (Nebraska). Homes were selected for visits on the basis of representing different models of care, resident population, sponsorship, geographical distribution, and "good" reputation. Common themes of the programs included close relationship between program philosophy and program realities, the key role of staff, an individualized approach to each person, the need for community programs and services, and a sense of community. (DB)

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COMMUNITY RESIDENCES

FOR

MENTALLY RETARDED PEOPLE

A STUDY OF SEVEN COMMUNITY RESIDENCES

by

Kurt Wehbring and Ciele Ogren

May 1975

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PREFACE

With the concept of a community based system of services for retarded people taking hold, and an increased effort to reduce the number of people living in institutions, there has been a dramatic increase in community residences for the retarded. Programs have been launched to develop community homes in several states including Connecticut, Washington, Pennsylvania, Florida, Massachusetts, New York and Wisconsin. Throughout the country groups of parents, concerned professionals and others are establishing small residential facilities for retarded people in their home communities.

Generally these organizing groups are like pioneers having to work out the concepts and practicalities of community residences on their own. Until recently there has been little information on the experiences of group homes -- both their successes and their problems.

To help provide parents, community home operators and professionals with information onthe emerging community residences springing up around the country, the National Association for Retarded Citizens commissioned this study of seven exemplary homes. The seven represent a diversity of sponsorship, size, organization, philosophy and program, as well as characteristics of the residents. They are not necessarily the "best" residences in existence. Although all the homes were recommended to us by knowledgeable professionals in the field as "exemplary", none is without some areas they feel could use improvement. In the case studies we have tried to describe the unique and positive features of the homes. It was not our purpose to critically evaluate these homes against a single standard, but rather to describe their approach and style which makes them unique and exemplary.

The following case studies describe the distinctive characteristics and styles of each of the community residences. Each represents a different approach based ondifferent conditions faced, type of resident and program philosophy. It is our opinion that the diversity in community homes is both to be expected and appropriate. Rather than a few models, many different kinds of homes need to exist in every community so that retarded people, like the rest of us, have a choice of residences to fit their own lifestyle and abilities.

Finally, we were both surprised and pleased by the

openness and warm reception we received from the community homes. We found the sponsors, staff and residents were proud of their home and willing to talk candidly with us. To the sponsors and staff, and most particularly to the residents who are delighted and challenged by the responsibilities of living in the community, we offer our thanks.

* * * * *

This study is arranged as follows:

The summary beginning on page three describes the highlights of each home followed by a comparative analysis of the home and our observations.

Each case study follows the general pattern of describing the origins and development of the home, the program and operations of the home, and observations.

A lengthier, comparative analysis is presented in the observations chapter beginning on page 220.

SUMMARY

I. HIGHLIGHTS OF THE COMMUNITY RESIDENCES

A. Manchester Group Home

As the policy of deinstitutionalization has taken hold, frequently there is a polarization between those who favor a community-based approach and those who favor institutions. Connecticut's Mansfield State Training School has demonstrated that such a polarization is unnecessary. This state institution has become a leader in developing community residences while at the same time improving conditions at the institution. Mansfield opened its first community residence in 1964. Since then nine more homes have been developed and in 1973 the institution was appropriated $1.6 million to open another 25 community residences.

The Manchester Group Home, one of the training school's original 10 homes, is a residence for 10 mildly and moderately retarded men ranging in age from 19 to 52 (median age is 33). Six of the men have spent long periods in institutions -- from 6 to 36 years; the other four came directly to the home from parents or foster parents. The home provides a sheltered environment so that the men are able to live and work in the community.

Seven of the men are competitively employed; two work at a sheltered workshop, and one attends school. Those who earn wages pay room and board based on a sliding scale.

The two houseparents, a couple in their fifties, live in the home and technically are "on duty" from 3:00 p.m. to 11:00 p.m. although in fact they are available whenever needed. They prepare the evening meal which the men eat together, order the food, manage the funds of the residents, help them find jobs, buy clothes, and settle disputes.

Mansfield State Training School leases the home, hires the houseparents, and provides a social worker who visits weekly to counsel the residents and help the houseparents resolve problems. For economy, groceries are ordered from the Mansfield commisary. Mansfield also has arranged recreational programs in the community for residents and provides transportation. In order to provide a day program for group home residents who did not have the skills to

participate in sheltered workshops, Mansfield organized the Hartford Project, a social skills and workshop program.

Some of the advantages of having an institution develop community residences are:

1. The administrative experience of the institution can be applied to developing homes. Furthermore the political weight of the institution can be used to obtain continued or new funding.

2. Because it is a relatively permanent organization the institution can assume long-term responsibility for care and help alleviate parents' concern about what will happen to their child if they cannot care for him.

3. There is a single organization accountable for quality.

4. Support services of the institution including diagnosis and evaluation, counseling, and transportation are available.

The danger is that the negative "culture" of the institution might be extended to the group homes. Through a conscious effort to avoid this, including a separate administrative unit, Mansfield appears to have avoided this problem.

B. Lupine House

Lupine House was founded by a group of parents in the San Francisco Bay Area who felt their teenage daughters would soon need a more independent life of their own. Although the founding group had no previous experience, within a year they were able to raise funds from a local foundation, locate a home, obtain a license, and find a house counselor. They were almost blocked by neighbors who claimed the home violated zoning regulations. However, mobilizing community support they were able to persuade the Planning Commission to permit the home. The home is a large, comfortable, private house in a woodsy, suburban neighborhood.

The program for the six, young, mildly retarded women emphasizes independence, responsibility and improved self image. Within the home these goals are put into practice by having the women do the cooking, cleaning, menu planning and shopping. The housemother acts as a teacher leaving as many learning opportunities as possible with the women. Outside the home all the women have a daytime activity. Two commute by bus to San Francisco to "normal," low-skill jobs; two are in vocational training programs, and two work at a sheltered workshop. Finding interesting work has been difficult. Even the two with "normal" jobs find them somewhat boring, though they enjoy the pay and the freedom of having their own income. Four of the women also attend evening courses in basic math and reading at the local junior college.

The home is governed by a 15 member Operating Board. In order to provide perspective and limit the tendency to be over-protective, only four of the 15 positions are held by parents. The other members are professionals and interested citizens. Day-to-day decisions are made by the housemother and the administrator. At first the administrator was a volunteer parent. However since a second home was opened, the administrator has been paid. Having an administrator outside the home has provided continuity and allowed the houseparent to concentrate on program rather than administrative matters.

Lupine House shows how a group of parents can establish a group home and overcome technical problems as well as community opposition. They have created a social environment that gives opportunities for growth and independence, while balancing the parents' concerns for the safety and well-being of their daughters.

C. The Hearth

Whether openly stated or implicit, the philosophy of a community residence is the underpinning of its approach, its program, its distinctive style and even its architecture. The Hearth in Erie, Pennsylvania, is the first residence established in the United States as part of a network of communities for the retarded called L'Arche (the ark) founded by Jean Vanier. Its philosophy is distinctively different from other community residences.

What makes the Hearth philosophy different is its Christian values. These include simplicity and poverty (in the sense of detachment from cultural riches), the importance of caring and loving between people, and the acceptance of retarded people simply because they are fellow men and women. Retarded people are seen as capable of experiencing deep spirituality, in part because of their "suffering" and partly because their intellectual limitations allow them to be more ingenuous -- to have fewer pretenses. In keeping with this spirit, distinctions between staff and residents are eliminated. At the Hearth the staff live with the handicapped rather than working for them.

The L'Arche philosophy gives retarded people a special value -- both intrinsically because they are human beings, and because they seem to have a unique way of being open, direct and loving. Because the Hearth is infused with this ideology, these qualities seem to emerge in residents, often having been dormant or hidden for years.

The Hearth provides a residence for up to eight mildly and moderately retarded men and women. Its style is that of a big family: everyone helps with the housework and meals. Celebration is an integral part of the life of the home: Celebrations of birthdays, religious holidays, a friend's arrival, a resident's departure.

The originators of the Hearth, a Catholic Priest and a Sister who taught at a local college, have intentionally worked to develop a community, not just a home. The community includes not only the residents of the Hearth, but neighbors and friends from the surrounding community. Frequently friends will drop in for a visit or join in the Sunday afternoon worship services at the home. The Hearth community extends also to other L'Arche communities: residents frequently visit L'Arche homes in Canada. In April 1974

the members of the Hearth flew to England for a pilgrimage with other L'Arche members to Canterbury. For several residents, it was the first time on an airplane.

The Hearth is interesting because it suggests a whole new way of relating to the handicapped.

D. Cheyenne Village

Cheyenne Village has developed a unique program which begins with highly structured living and training and leads to independent living in a series of steps. The first step is closely supervised living at McLaughlin Family Lodge, a 27 unit motel near Colorado Springs. Seven of the units are used by 30 retarded people who, as part of the structured training program, work at the motel. The motel work -- cleaning rooms and maintaining the grounds -- provides a real work experience as well as an opportunity to observe and meet normal people. When a resident has shown sufficient ability to work at a job and take responsibility for his own life, he moves to the staffed Training Apartments in Colorado Springs. These are two duplex apartments where 14 men and women are trained in community living skills such as cooking, shopping and using community recreation programs. The next step is Counseling Apartments where the resident lives on his own in a normal apartment with a roommate. These apartments are scattered throughout the community. Staff counselors visit in the evening to work out problems as they arise and provide support to keep the residents from regressing. In the final step -- independent living -- counselors no longer visit residents; however, Cheyenne Village's commitment continues, and staff is available whenever a former resident needs help. In the first three years of operation 14 residents had progressed to Counseling Apartments and 5 to independent living.

To help residents become self supporting, Cheyenne Village has an extensive occupational program. Training is focused on job habits and attitudes rather than specific skills, since it has been found that absenteeism, disputes with employers and similar problems are the main cause of job loss by the residents. Counselors assist residents in finding jobs and working out on-the-job problems which arise later.

A cornerstone of the program is a "reality approach" whereby residents are held fully responsible for their actions just as normal people are. Staff work constantly with residents to overcome dependency and irresponsibility patterns fostered by over-protective parents or institutions.

An innovative feature is the weekly resident-staff meetings, usually chaired by a resident. All residents who live at the motel and staff participate in what is a cross between

a New England Town Meeting and group therapy. For a resident to progress from the initial high level of supervision to a less supervised status he must "ask for his independence." Staff members then make frank comments about the resident's progress (or lack of progress) and a decision is arrived at.

Bill

Bill is a tall, lanky man of 23 with an extraordinary fondness for animals. Whatever his disabilities, his abilities are more noticeable: a determination to be his own man; ability to take care of himself including living alone and driving a car; a flair with the electric guitar; and his way with animals which he puts to use at his job with the Humane Society.

At age 21 Bill came to Cheyenne Village from a state institution where he had been for 6 years. Within eight months at Cheyenne Village he was able to move to a Counseling Apartment. The staff found a trailer for him so that he could live independently and he is slowly paying for it. With the help of the Village he regained his legal rights. At times Bill is defiant of the Village's overseeing role, but he is on good terms with the staff and knows when to come to them for assistance such as buying and registering a car. With such support, Bill is able to live his own life on his own terms.

Cheyenne Village is offering some 70 people in a single package, a program of living skills and work training, levels of residential care with each step being more independent, and long-term support for those who have reached independence.

E. Community Living Project

While many planners and staff of community residences agree that independent living is an implicit goal of normalization for mildly and moderately retarded adults, they do not always agree upon the ingredients necessary to spawn independence. Staff of the Community Living Project in San Diego, California emphasize two ingredients they feel are crucial to independence: taking personal responsibility, and making sound judgments. Accordingly, residents in training are allowed to experience the consequences of their actions and are given choices and alternatives requiring them to make decisions of their own. These freedoms to make mistakes are balanced by a supportive atmosphere with built-in successes and readily available counseling.

The Community Living Project is an urban apartment community where twenty-six young adults with learning disabilities live in their own apartments in a large two-story apartment complex. It was developed in 1972 by a group of professionals with the leadership of a Salvation Army social worker. While practicing at managing their own lives, residents attend evening classes two or three times a week where they get one-to-one training in cooking, household management, and budgeting. In these sessions residential counselors take an individualized approach to training and use a variety of teaching aids such as tape-recorded recipes and budgeting envelopes labeled with pictures. Residents get additional training in larger group meetings that include the entire apartment community. Social expression, legal rights, health, and interpersonal relationships are among the topics and skills covered in these educational presentations that are followed by small group discussions. Here, too, innovative techniques are used to make the learning more effective. In learning about fire safety, a safety officer set a fire in the alley, and the residents practiced using a fire extinguisher to put out the fire. In learning about decision-making, tenants role-played scenes with door-to-door salesmen and "borrowing" neighbors.

Many aspects of the program indicate that the staff (three resident counselors and a full-time social worker) strive to find and maintain the tenuous balance between freedom and support. Staff have a basic trust in the abilities of the tenants to succeed that is exhibited in the freedoms offered. For example, tenants manage their lives and apartments with a minimal number of rules imposed by the project. They are responsible for the payment of bills

to the extent that the staff will allow utilities to be disconnected when bills go unpaid. Further, throughout the training tenants are given alternatives and choices to exercise their decision-making ability. Staff honors the tenant's choices on an individual basis. In one case a young man who collected antiques was given special permission to pursue his hobby as his selected daytime activity rather than working or training. To balance these freedoms, support is given. Dedicated staff are available for counseling nearly every evening, although tenants are sometimes left without staff available so they may work things out by themselves. Resident counselors tailor training so that successes are built in -- some tasks are purposefully easy to accomplish. Tenants have also developed their own supportive network among themselves: observers are keenly aware of the friendships and sharing that have resulted from their living together -- an important ingredient in their development of pride and confidence in themselves as individuals.

In addition to its unique program, the Community Living Project also has a unique structure. The apartment building is a leased-housing facility used by special permit from the Public Housing Authority. Tenants apply for their own apartments, qualifying on the basis of their low incomes, paying low rent that is within their small budgets. When their training is complete, they can move to another leased-housing facility. The advantage for the project sponsor is that the building was obtained with no capital outlay.

Administration and operation of the project is shared by the Salvation Army's Bureau of Social Services and an Advisory Committee. As the sponsoring agency, the Salvation Army plays a major role in determining whether or not program ideas are financially and operationally feasible and in obtaining funding. The Advisory Committee is a sophisticated committee composed of Salvation Army staff and volunteers, staff of the project, parents, and staff members of a dozen community agencies. Many of the same community agency people worked together through the year of planning for the project, demonstrating the effectiveness of a collaborative agency effort.

After a year and a half to two years of training, graduates have moved to other apartments in San Diego and are able to manage their lives independently with a minimal amount of support from the project. Staff visit with graduates once or twice a week to help with problems, and graduates return to the project frequently to visit friends. Both graduates and staff are pleased with the success of living independently in the community.

F. Lori Knapp Home

Many community residences are working well for mildly and moderately retarded persons able to gain skills necessary for living in the community, but few have met the challenge of the severely retarded. The Lori Knapp Home is showing that it is possible for a community home to meet their needs. Eight severely and moderately retarded children, most with physical handicaps as well, are blossoming from the effects of their home in Prairie du Chien, a rural town of southwestern Wisconsin.

Lori Knapp Home was founded in 1972 by Donald Knapp, father of one of the residents. His dream to bring his daughter home from the institution to her own community, came to fruition through the support of the State Bureau of Mental Retardation, the State of Wisconsin's agency for Community Living Systems. The state institution, Central Wisconsin Colony, supervises the home and has provided training for the staff, a major ingredient in the success and quality of the home.

Being a home for children, emphasis is on life like that of any normal family. The general atmosphere of the home is that of a caring and cooperative family. As in all large families the older children help with the younger children. Only here helping a "brother" or "sister" often means lifting him if he can't walk, or feeding her if she can't feed herself. The house staff (houseparents, relief houseparent, part-time aide, and cook) have been selected for their abilities to be warm and loving parent substitutes. They give nurturing, guidance, supervision, and discipline with a firm but loving hand.

This family atmosphere is the spontaneous outgrowth of the relationships that have developed between the people both inside and outside the home. Although the original expectation was that the children and the houseparents would form a family unit, more has occurred. The immediate family has extended to include families of the Knapps and the staff and the adults at the nearby Knapp Adult Home (a similar home for adults located across town from the children). These relationships have grown spontaneously through repeated encounters with one another and are the result of the genuine interest and caring between the people. The growth and changes in the children reflect their security in this environment.

The house itself also enhances the quality of living in the home. Special features of the house make it very nearly

ideal in meeting the children's needs. Since the children were selected prior to the building of the two-level ranch-style modular home, the house was literally designed for them. Some of the special features are wide hallways and doors (a must for speeding wheelchairs), an electric chair lift between levels, and two bathrooms with specially designed toilets, tubs and showers.

Daytime activities include TMR classes for six of the children, and Personal Development Center for the other two. After school, on weekends, summers and holidays it is clear that a high value is placed on fun. Picnics, walks, swimming at the adult home pool (an indoor heated pool used year round by several community groups), parties, barbecues, Special Olympics, and Badger Camp (a summer camp) are among their favorites.

Lori Knapp Home is clearly a quality home, due primarily to the attitude and relationship of the staff to the children, and to the valuable supervision of the institution. But it is not without its problems and limitations. Sometimes the composition and size of the home pose management problems: eight is a large number of children, especially since four of them are non-ambulatory and two require extensive care. It is difficult to incorporate the physical and occupational therapies the children need daily into a normal home setting with a very busy schedule, so this requires constant attention. And the home needs a busvan equipped with a power lift and storage places for wheelchairs and crutches. Without such transport it is difficult to make excursions in the community. However, greater problems have been overcome: obtaining community acceptance of the home; integrating the children into the mainstream of life and the community; circumventing attitudes and treatment of the children that would limit their leading normal lives.

The home is a result of a state plan that utilizes proprietory homes as a primary model for community living. Advantages for the state are that the homes are relatively easy to start since the proprietor assumes primary responsibility for operation and style of the home. A disadvantage is that it is more difficult to raise the quality of homes when needed. In order to maintain quality, the plan calls for the state institutions playing an active role in providing community consultation, staff training and supervision.

G. Hamilton Street Residence for Children

More than four years ago, shortly after the President's Committee on Mental Retardation identified normalization as the most important principle in developing services for mentally retarded people, a forward-looking parent group in Omaha, Nebraska (GOARC -- Greater Omaha Association for Retarded Children) put the principle into action. In 1970, after much searching for a suitable house, they located a brick duplex in a transitional residential neighborhood, remodeled it, and opened a community residence for six moderately and severely retarded children in need of intensive training for behavior problems. The effort was courageous since professionals predicted that several of the children were incapable of further growth.

Not long after GOARC opened the home, day-to-day operation of it was assumed by ENCOR, a comprehensive multi-county system that now serves more than 1,000 mentally retarded persons. This cohesive network includes residential, vocational, developmental, recreation, counseling, evaluation, and transportation services. Themes of the services are: integration into services for the non-retarded; dispersal of service clusters throughout the community; movement through continuous services; spin-off of services (ENCOR only fills service gaps); flexibility and change; evaluation, internally and externally. All the services are permeated with the philosophy of normalization, applied to even the smallest detail.

At the Hamilton Street Residence the staff attempts to maintain a home that is as normal as possible through promoting a family atmosphere, particularly at mealtimes and bedtime. They attend to details like insuring that belongings are appropriate to the children's ages and avoiding demeaning lables in referring to behaviors or physical conditions of the children. Maintaining the family atmosphere has to be juggled with meeting the special needs of the children, while still providing for freedom and exploration. To do this, staff view the children first as whole individuals in need of freedom, and secondly as children with special needs -- an approach that is not always easy since some of the children have problems such as tantrums, rocking, and headbanging that are difficult to handle.

The special needs of the children are met with a fairly intense behavior modification program, monitored with Precision Teaching charts and tools. The program is approached

in a humanistic way, using positive substitutes for inappropriate behaviors rather than negative consequences used by similar programs elsewhere. The staff also accentuate the strengths of the children, ignoring difficult behavior and reinforcing more desired behavior. Though "programs" are used for a good part of the time the children are home, they are also given free time to explore and play by themselves. During the day the children attend public school classes or Personal Development Centers, where attempts are made to coordinate behavior modification methods and programs with the home.

The home is staffed by a young houseparent couple, an assistant houseparent, and four residential assistants who work a total of 280 hours a week. The large staff is necessary both to meet the special needs of the children, and to meet the administrative obligations of working within a large system. Besides managing the home, the staff does things like assessing the training and physical needs of the children, attending teacher's meetings and ENCOR meetings, and keeping behavior modification records. An additional new responsibility is supervising and coordinating Alternative Living Units -- satellite homes in the community where several of the children have recently moved.

Hamilton Street Residence is administered by the Residential Services Division of ENCOR. This division has five area coordinators who are responsible for the overall supervision of community residences. Hamilton Street Residence is supervised by the area coordinator for the district in which it is located.

This home indicates that severely and moderately retarded children with complex behavior problems can grow and mature beyond expectations of parents, professionals and staff, in a community-based residence. The home also demonstrates the role of a comprehensive service system in the operation of a community residence. The advantages of such a system are several:

-- a comprehensive system has the ability to procure funding that might not ordinarily be available to a smaller organization;

-- it can provide residential services that are more cost beneficial by spreading costs over a number of residences;

-- program plans for individuals can more effectively be coordinated among services within one system;

-- it can provide its own residential steps, thereby insuring movement for the resident who needs it.

A disadvantage of the large system might be its cumbersome bureaucracy that creates a long if not distant link between the administration and residential staff. A notable ingredient in the success of this system, however, is its commitment to change. This openness and availability to new programs and ideas gives the system its life to sustain itself.

Table 1

COMPARISON OF COMMUNITY RESIDENCES

NAME	SPONSOR	GOVERNING BOARD	NUMBER OF PEOPLE	UNIQUE FEATURES
1. Lupine House	Parents/ARC	Parents & professionals	6 mildly & moderately retarded women	Warm, home-like atmosphere; housework and skills training; parent involvement; outside administrator; housemother as counselor.
2. Community Living Project	Salvation Army	Mainly professional	26 men & women moderately & mildly retarded	Training of residents by counselors; emphasis on making decisions; community feeling; a transitional arrangement to independent living; collaborative inter-agency effort; Public Housing Authority facility.
3. Manshester Home	Mansfield State Training School	Institutional Board only	12 mildly & moderately retarded men	Started by an institution; back-up program by institution; leisure-time program; employment assistance by houseparents.
4. Hamilton Residence	ENCOR	ENCOR Board only	6 severely retarded children	Part of a system of services; use of behavior modification program; normalization philosophy carried out in detail.
5. Lori Knapp Home	Parent originated	None	8 moderately to severely retarded boys & girls; 4 non-ambulatory	Warm, family atmosphere, extended family includes adult home; in-home program for severely retarded children; organized by a parent; supervised by state institution.
6. Cheyenne Village	Group of parents formed non-profit corporation	Interested citizens and parents	70 mild-moderately retarded men and women	A development and training program leading to independent living; reality approach stressing self responsibility; support of interested citizens.
7. The Hearth	Small group of committed religious individuals	Interested citizens and professionals	6-8 mildly & moderately retarded men and women	Residents and staff live together; spirituality; celebration; vision of retarded as people with intrinsic worth; strong sense of community.

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II. COMPARATIVE ANALYSIS

Initiation of the Residence

A tradition in the mental retardation movement is the strong role parents have played in developing services for their retarded children. It is not surprising, therefore, that the genesis of the community residences in this study is mainly with groups of parents. Of the seven homes, four were started by groups of parents who were faced with having no suitable living alternatives for their children. However, these parent groups did not work alone. In each case they were able to enlist the support and cooperation of professionals in working through the necessary details and moving their idea from a concept to a reality. The parents carried out many valuable functions: generating enthusiasm and support for the residence, raising funds, seeking out staff, working out the legal arrangements, finding a suitable facility, frequently locating prospective residents, helping establish the philosophy and approach of the home, and maneuvering politically when community opposition or zoning issues emerged. The professionals, working in partnership with the parents, provided assistance in technical areas such as obtaining funding, meeting licensing and code requirements, and being a guide and facilitator in meeting administrative requirements. Professionals also were influential in helping to shape the ideology and program of the homes. Frequently they were a counterbalance to the parents who tended to be over-protective of their children and preferred a more sheltered environment than what evolved.

The three homes not initiated by parents are equally instructive. The home in Connecticut (Mansfield) was started by an institution which had developed a community residence program. The institution's new administrator was aware that many residents of the hospital could function in the community. He also recognized that community living could be substantially less expensive than institutional living. San Diego's Community Living Project, was initiated by a group of professionals with the leadership provided by a Salvation Army social worker. The committee of agency representatives she assembled recognized there was a lack of community residences and particularly a training program to prepare retarded people for community living. The Hearth, on the other hand, was started by three

individuals who had previously little experience working with the retarded. They were motivated by the example provided by the L'Arche movement, and after hearing Jean Vanier, its founder, describe his experiences, came to see that their calling would be in opening a home.

The development of community residences is relatively new in the United States, and all of the founders of homes had little information about the process when they started. (The one exception is in Connecticut where the Mansfield Training School had been developing homes for several years and thus had accumulated experience.) In their efforts to educate themselves, the forming committees frequently visited other community residences. The Hearth founders spent time at L'Arche homes in France and Canada, and the original staff of the Community Living Project had visited homes in Scandinavia on a Dybwad fellowship. Cheyenne Village founders visited a number of homes in other states and hired a consultant to do an economic feasibility study of their concept.

Because of the lack of available information and experience, the planning period took an average of 12 to 18 months. In the case of Cheyenne Village it required over three years from the time of original commitment to the time the program was started. No doubt the planning period could be shortened and the process made less difficult if furture founders of homes could be provided with information and technical assistance in forming the home.

What is most impressive is that the founders were able to establish the homes with so little guidance and precedent. Four of the homes (Lupine, Hearth, Cheyenne Village and Lori Knapp) were organizations started de novo. That is, they had to create an organization to guide and manage the homes. In three cases (Manchester, Community Living Project and Hamilton) there were existing organizations which provided a base onto which the home was added.

Whether a new organization was formed or an existing one used as a launching platform, the development process followed a similar course in all but one of the homes (the exception is Mansfield where a program and office was established for developing a home). The development process was initiated by one to three individuals who became concerned about the need for a community residence and would enlist the support of others. A period of discussion and sometimes study would ensue where the need was further defined and possible steps

outlined. At some point the initiators would make the decision to go forward and a commitment was made -- either a house obtained, funds donated, or in some other way a specific, tangible step made that moved the process from discussion to action. Although their problems were only beginning, the founders were able to make the commitment to action and begin developing the facility.

Development of the Residence

Finding a suitable building in a convenient location soon became a primary focus in the development process once the decision to go forward had been reached. All but one of the residences studied used existing buildings. The exception was the Lori Knapp home which was developed as a standard single family home with modifications such as ramps for wheelchair access, wider doors and adaptations in the bathrooms.

The variety of arrangements that were devised for obtaining a facility reflects the ingenuity and persistence of the organizers. Two of the residences are in large private homes that are leased from a private owner (Lupine House and Manchester). Two others are in single family houses that were purchased by the sponsoring organization (the Hearth and Hamilton Street Residence). Cheyenne Village is a combination of facilities: operating motel that was purchased by Cheyenne Village, part of which is used as residences while the rest continues as a motel, three homes in the community which are leased by Cheyenne Village and used as halfway houses, and a number of apartment units scattered throughout the community used by residents in the final stage of the program. The Community Living Project in San Diego was able to obtain the use of an apartment facility through the leased housing program of the local Housing Authority.

In finding a home, a number of locational factors were shared in common: a pleasant neighborhood where the residents would be safe, available public transportation, proximity to likely places of employment, and special programs. Inevitably there was the need to consider the trade-offs between the locational factors. Large, old houses that are within a suitable price range frequently are in older, less desirable neighborhoods. On the other hand, an older neighborhood such as where the Hearth is in the "grey area" -- the older residential neighborhoods near the central business district -- have a mixture of different types of people and persons who are somewhat different are more easily tolerated.

Most of the homes needed some minor alterations or additions to make them suitable for group living. Typically some safety features such as smoke detectors or alarm systems were required by fire codes. Although these fire and safety code requirements were not a difficult problem in the homes studied, in other cases we are aware of, such requirements have put a heavy financial burden on small group home operators who do not have resources to deal with these. The Community Living

Project, for example, when they were initially searching for a facility found that if they wished to start a home with more than six persons they fell into a category of facility that had stricter fire and safety requirements than a small "family care" facility (in California, less than six persons), and that meeting code requirements would be too costly.

Licensing requirements were able to be met by the homes without too great difficulty. However, a few incidents suggest the type of problems that can develop if licensing requirements are too rigid or inflexibly administered and go counter to the direction of having community residences to be like homes rather than institutions. In Lupine House, licensing regulations require supervision at all times so that a resident could not return home early to the home since the house counselor did not come on duty until the late afternoon. Another irritating and non-normalizing situation was that the residents needed a physician's prescription in order to take skimmed milk in their diet.

Zoning created some difficulties in three of the seven homes. The account of Lupine House's difficulties are typical of the kinds of community fear and misunderstanding that has occurred in a number of cases around the country. In the Lupine House and Lori Knapp experiences, community opposition was overcome through persisteht efforts at explaining the project and rallying supporters of the project who were able to persuade the Planning Commission to permit the homes. In the case of the Hearth, a request for rezoning to permit a larger number of persons in the home was accepted after more than a year of deliberation.

Once established, the homes and residents have had good, if somewhat distant, relationships with neighbors and the community. Indeed there are occasions when those who opposed the location of the home have subsequently turned into friends and supporters of the home. The Hearth provides an interesting example of interaction with people in the neighborhood and community. The Hearth organizers consciously work at establishing a sense of community at several levels: within the house, with neighbors and friends in the community, and between other L'Arche communities. Neighbors drop in to pass the time and there is visiting to and from other L'Arche communities.

Operations of the Residence

The way the homes work from day to day is a product of a number of ingredients: philosophy and goals underlying the development of the home; staff capabilities, attitudes and ingenuity; abilities and personalities of residents; community resources available. The influence of each ingredient is strong, and each is varied in itself by the complexion of the conditions and personalities involved. Therefore, it is not surprising that though similarities exist among operational ingredients, no two residences come out looking and working the same.

Philosophy

Whether implicit or explicit, philosophy and goals were of great significance in shaping the operations of the seven homes. Most of the homes claimed they were following the normalization principle, but what this meant in the practice of each home was quite different. In applying the normalization principle most of the homes gave attention to things readily observed as "normal." Examples were: creating a home-like atmosphere where decor was warm and comfortable; age-appropriateness of the possessions and dress of the residents; referring to residents in a non-demeaning manner.

However, the actual goals of the homes were developed from local needs, perceptions, and experiences. These specific goals were quite varied. For example:

-- providing a long-term, sheltered home
-- training residents to live on their own
-- developing self-esteem and skills
-- helping residents to learn to make decisions
-- reducing the population in institutions

Independence was a specific goal for most homes that was seen in the provision of residential steps that were increasingly more independent, and in the attention to development of skills necessary for making it on your own. Two residences emphasized self-responsibility in a specific way: Cheyenne Village in its use of "reality therapy" (allowing residents to experience the consequences of their actions) and Community Living Project in creating alternatives requiring residents to make decisions and develop good judgment. Implied in nearly all of the programs as well, was concern with self-worth and self-image. Lupine House was specific about it in their policy

manual, indicating "improved self-image" as a specific goal. Community Living Project is careful to "build in successes" in order for residents to continue to value themselves during training. The Hearth responds in word and deed to the unique value and spirit of the retarded, particularly in the staff's equal relationships with residents. Most of the homes also saw decreased aberrant behaviors, increased integration with the community, and job success as means by which residents could increase self-esteem.

Children's homes and adult homes alike shared the tenuous task of balancing and juggling freedom and support. Staffs of the Community Living Project and Hamilton Street Residence commented specifically on the difficulty of allowing residents sufficient freedom to explore and experience their own rights and autonomy as individuals, while at the same time providing adequate support for continued growth and special needs.

Staff

Next to program philosophy, staff are a most critical factor in the operation of a community residence. When asked what qualities make a good staff person for a community residence, administrators mentioned: good health and vitality, patience, endurance, innovation, ability to be organized, confidence, and a basic belief in the capabilities of mentally retarded people to grow. This last is perhaps the most important characteristic. It includes the ability to find ways to allow a resident to grow and develop, even when they make mistakes. Previous experience working with the retarded did not seem to be as significant as these qualities, although nearly half of the staff of the residences studied had prior experience.

Initially, staff selection was largely a hit and miss affair since most of the home administrators had no prior experience in operating homes. They did not know what qualities to look for in potential staff. Most residences placed ads in local newspapers describing the positions to be filled as houseparent, counseling or teaching jobs, and were consequently deluged with applications from seekers of people-oriented jobs. Initial selections were based almost entirely upon the intuition of administrators.

Several administrators found that a person who takes the job out of his own need to be needed, is not a good choice. To be effective a staff person needs to have a

sense of self that allows him to get a lot out of his own life which at the same time gives him the ability to tolerate freedom for the residents. One home soon discovered that their first housemother, who gave up her own personal life, was not able to give the women residents what they needed.

Typically, staff in the homes studied were single people or young married couples, in their twenties, and most with one or more years of college education. Exceptions included a couple in their fifties (Manchester), a priest and nun in their thirties (Hearth), and Cheyenne Village, started by a couple in their thirties and employing mainly single, young adults.

Experience also taught home administrators that because of the heavy demands for attention upon the staff, the lack of privacy, low pay and other changes in life circumstances, even the young, energetic staff would stay only an average of one to two years. Some administrators have simply accepted this as the "burn-out" syndrome, and view counseling and houseparent jobs as short-term ones. A benefit is that new staff can add new energies and ideas to the program. A disadvantage is that it is sometimes very difficult for residents to adjust to the change, particularly since some residents are for the first time in their lives enjoying a primary relationship with caring adults who are consistently available to them.

Staff turnover and "burn-out" are realities of community residences. Regular hours and adequate vacations would help alleviate some of the pressures on staff.

Residents

Of the seven community residences studied, five served primarily mildly and moderately retarded adults, while two homes provided community care for severely retarded children. Many of the residents at Cheyenne Village, while only moderately or mildly retarded, also had behavior problems and had been in trouble at established institutions. (See Table 2.)

Program

Since most of the residents of the homes were new to the community, administrators planned in-home and out-of-home activities focused primarily on training to live in the community.

Table 2
RESIDENTS OF THE COMMUNITY RESIDENCES

Community Residences	Residents		Ages	Level of Retardation	Other Disabilities	Prior Residences
	Men	Women				
Manchester	10 men	----	19 - 52 (median 33)	mild-moderate	1 blindness 1 epilepsy	6 - parents 4 - institution (6-36 years)
Lupine House	----	6 women	17 - 32	mild-moderate	1 slight speech impediment	6 - parents
The Hearth	4 men	3 women	17 - 40	mild-moderate		mainly from institutions
Cheyenne Village	35 men	38 women	17 - 40	mild-moderate	behavior problems	home and institutions
Community Living Project	16 men	10 women	18 - 44 (most in early 20's, 3 over 35)	mild-moderate	muscular dystrophy, cystic fibrosis, epilepsy, diabetes	15 - parents/family 4 - institution 4 - community but doing poorly
Lori Knapp Home	4 boys	4 girls	10 - 17	moderate-severe	4 - non-ambulatory	8 - institution
Hamilton St. Residence	4 boys	2 girls	10 - 12	moderate-severe	hydroencephalus par-encephaly spina-bifida cerebral palsy	4 - institution 4 - parents or foster homes

In-home programs consisted of practical and social skills, while out-of-home programs were educational, vocational, sheltered work experience, or competitive jobs.

While the general skills areas given attention in in-house programs were much the same, the intensity and style of the training approach was greatly varied. Lupine House used household chores as means for teaching household management, so the women residents did all the household work, and the houseparent provided only guidance. The Community Living Project residents were responsible for their own apartments including cooking their own meals. Counselors met residents in their own apartments for one-to-one training sessions in cooking, household management and budgeting. Even more structured training occurred at Cheyenne Village where training had three specific parts (living skills, vocational adjustment, social adjustment) with concrete steps of progression leading to independent living. In contrast, the Hearth simply allowed training to occur as the spontaneous result of living together. Themes in all the in-home training programs were self-discipline and responsibility to each other.

The two children's homes in the study, in addition to the usual living skills training, had special training programs for the children who were moderately and severely retarded with additional handicaps or behavior problems. Lori Knapp Home used firm but loving discipline in accomplishing living and behavior skills, combined with physical therapy and occupational therapy (primarily motor feeding skills) for the children with physical problems. Hamilton Street Residence used humanistic behavior modification to teach both living and behavior skills for children with rocking, headbanging and tantrum behaviors. (See In-Home Training Program Chart.)

In all of the homes residents went to out-of-home programs during the day. Adults went to school, sheltered workshops, vocational training programs or competitive jobs. In the smaller homes, houseparents helped residents find suitable jobs. In the larger, more comprehensive programs like ENCOR and Cheyenne Village, there were vocational training programs where residents began working at jobs closely supervised by program staff, and worked progressively toward jobs in industry or contract jobs held by the program. One interesting aspect of the job training was that these programs have job stations in industry where a program supervisor goes to work with residents to aid them in mastering skills required by the industry. Both these programs have found that the social aspects of the jobs rather than technical skills are the most

Examples of specific training areas for in-home training: (selected items from training skills outlined by ENCOR and Community Living Project)

Self-management:	attending, body motor skills, hand motor skills, toileting, self feeding, personal hygiene, dressing, clothes selection and maintenance, grooming, posture, health care, corrective devices
Communication:	non-verbal, verbal, verbal characteristics, response to social environment
Inter-personal relations:	group participation; care and sharing of property; table manners; interaction with others; recreation
Environmental structuring:	coping, distinguishing properties of objects; time management
Environmental access:	telephone usage, media usage, transportation, eating away from home; community activities, community orientation
Household management:	money management; meal preparation and storage; grocery shopping; shopping for personal items and household goods; housecleaning and laundry
Other:	emergencies, first aid, legal rights, sex education

difficult for residents to grasp and most important in holding a job: being punctual, showing up regularly for work, being responsible to see the job through to finish, getting along with fellow workers.

Approximately one-third of the residents in the homes had competitive jobs. They liked them for the money and the independence this gave them, but the jobs themselves, residents often said, were dull and repetitious. The consistency with which this was reported, emphasized the problem retarded people have in finding satisfying jobs in a high skills oriented job market.

Children attended TMR and EMR classes in the public schools or Personal Development Centers which concentrated on perceptual and motor skills. In both homes attempts were made to coordinate in-home and school teaching. With the new laws requiring public schools to accept responsibility for the education of every child of school age, community residences are looking forward to working even more directly with public schools to develop adequate programs.

Program Results

The results of these programs are best described by the progress of the men, women, and children who have all benefited greatly from living in the homes. The following vignette demonstrates the magnitude of the changes that have occurred as a result of community living. (See case example pg. 30.)

Costs

The per person costs ranged from a low of $2,075 to a high of $11,137 per year as shown on Table 3, page 32. Comparisons between homes are somewhat misleading for several reasons. First, there is no common accounting practices for such homes so that the figures are not always comparable. Secondly, many of the homes received services from volunteers which often were not accounted. Thirdly, many of the budgets are for the early years of operation before the program and its costs have stabilized. Finally, because of inflation, present day costs are undoubtedly considerably higher than during the reporting period.

Murray

A ten year old boy, who we will call Murray, is the "miracle child" of a home in Omaha, Nebraska. He is a small, thin little guy with longish blonde hair that helps to disguise his elongated, unusually shaped head. He came to the home from the state institution four years ago. Doctors had predicted that he would not live beyond five years of age, and that he would be totally non-functioning. Since he had not been expected to live, he had been excluded from programs at the institution, and just sat or laid in his bed staring at the walls until he was nearly six years old and was placed in a community residence.

Now Murray can not only walk, but run and ride a tricycle. He talks quite well, often repeating what a person says as if to capture its meaning. He is a lively child who goes to special education classes at the public school, can read, and add and subtract. In fact, the staff of the home think he is being held back in the TMR class and are making provision for him to be moved to a more challenging classroom next year.

He has now moved from the training residence, along with a little friend (also from the residence), to the home of a family in the community where his new "parents" are being supervised as home teachers by his former housemother. (ENCOR's new model of residential living called Alternative Living Units.)

In all of the homes personnel costs took up the greatest part of the budget: an average of 56 percent. Staff costs ranged from a low of 34 percent to a high of 73 percent. In a home with more handicapped people, as might be expected, staff costs were higher and consequently per person costs were also high.

Advocates of community residences frequently claim that they are less expensive than institutional care. While this may be the case, a comparison of these or similar figures to institutional costs may not be correct. Institutional costs frequently include a number of program costs (such as behavior training, educational and recreational programs, and medical care) which are paid for in other ways that do not show up on the balance sheet for community residences. Quality care, whether it is in the community or in an institution will not be cheap.

Funding Sources

Finding the funds to support the homes has been a challenging task and one that has been responded to with great drive and imagination. Typically the organizers had to raise funds from friends and local foundations to provide the initial money to get the project off the ground. Once started, a number of different sources: federal, state and local -- have been found to pay for operating expenses.

Cheyenne Village's approach is suggestive of the way different sources of funds can be brought together to pay for different pieces of a total program. Room and board costs while a resident it at the motel are paid for through Federal Supplemental Security Income (SSI) payments. When residents move to the counseling apartments they pay their own room and board from wages they earn. The personal and social growth programs are paid through a program of which the Federal government pays three quarters and the locality, one fourth. Vocational Training funds pay for the salaries of the job counselors, while separate state funding pays for job placement and follow up. As funding sources change, no doubt the program will adapt.

The Community Living Project was able to pool together funds from general revenue sharing, the regional center, the State Developmental Disabilities program and local foundations and agencies.

Table 3

COMPARISON OF COSTS OF RESIDENTIAL FACILITIES

Item	Manchester	Community Living Project	Lori Knapp	Hamilton Street (ENCOR)	Lupine House	The Hearth	Cheyenne Village
1. Housing	$ 8,934	$12,900	$10,706	$10,008	$ 6,740	$14,622	$ 46,640
2. Food	5,007	--**	6,600	7,300	4,500	3,672	27,500
3. Personnel	16,487*	39,290	11,220	45,535	18,121	10,225	216,000
4. Miscellaneous (licensing, accounting office expenses, education)	400	870	780	2,700	1,778	350	6,800
5. Transportation	na	900	300	1,200	850	880	na
6. TOTAL COSTS	$30,828	$53,960	$29,606	$66,823	$31,989	$29,749	$296,940
7. Number of residents	10	26	8	6	6	6	86
8. Cost per resident per year	$ 3,083	$ 2,075	$ 3,700	$11,137	$ 5,332	$ 4,958	$ 3,452
9. Budget year	73-74	73-74	73	74-75	74	74-75	74-75

*Includes $3,000 for social worker's time.

**Food purchases are made by residents from their own sources.

na Indicates not separately accounted.

Sources: Cost figures submitted by facilities.

Observations

Need for Diversity

These seven exemplary homes are strikingly diverse in their styles, philosophy, size, sponsorship and characteristics of residents. This diversity in the community residences is reported by others doing national surveys of community residences.

We believe this is a healthy diversity. The community-based approach to care for retarded people is in its early, formative years. It is a time for experimentation. Furthermore, retarded people are very different in their abilities and preferences. They deserve to have a choice in where they live.

Importance of Program Philosophy

The program philosophy is like a hidden hand which influences even the smallest details in the home. Who prepares meals? Can residents be home alone? Should there be group or individual activities? The decisions on these and hundreds of other programmatic questions are influenced by the program philosophy which guides the home. Frequently the philosophy is only implicit. However, we believe that it is well worth the time and effort it takes to carry out an extended dialogue to shape, and indeed reshape, the philosophy.

The concept of the retarded person and the goals of the program appear to have the greatest influence on the program philosophy. If the retarded person is perceived as being able to learn and grow, then the program philosophy leans towards independence and self responsibility.

There were a variety of goals in the homes. Most have more than one goal. They included:

- -- providing a permanent residence
- -- training residents so they can live on their own
- -- fostering a sense of community
- -- influencing society by providing a model of human community
- -- providing a long-term protected environment to alleviate concerns of parents about the care of their children when they cannot care for them

-- reducing public costs of caring for retarded people
-- decreasing the population in state institutions
-- altering adverse social behavior so that retarded people can live in less structured environments
-- providing an atmosphere for human growth and development

Each home found its own balance between providing both support and individual freedom. Institutional living and over-protective parents often prevent learning by removing risk and uncertainty. One parent was too fearful to allow his son to drive when he lived at home. Now that he has progressed through the Cheyenne Village training program and lives on his own, he drives his own car. In the homes studied, personal growth and development was greatest where residents were allowed ample freedom to learn and develop.

Key Role of Staff

Of equal importance to philosophy in setting the style and tone of a home is the staff. Because of staff's position of authority, their ability to direct the activities in the home, and the lack of outside influences in the home environment, staff are able to set the tone of the home.

Staff viewed their role in many ways: teacher, counselor, advisor, and substitute parent. Most of the homes where the residents are adults the role of substitute parent was avoided because it was not seen as "normalizing" and encouraged dependency patterns.

Effective staff had the basic human qualities of awareness and sensitivity to others, genuine interest in relating to the residents as fellow human beings, a willingness to allow them to learn and grow, and the energy, ability and patience to live with the frustrations and demands of such a relationship. Jean Vanier who founded L'Arche says what he looks for in staff is a certain shine in a person's eyes when they talk about matters of life.

Individualized Approach

Time after time we noticed how each person was related to as an individual, and given special attention: a rule modified, extra assistance given to handle a situation or a special firmness to help a resident meet a responsibility. The individualized

approach is a particular benefit of small numbers possible in a community residence. With fewer residents staff seemed to be more flexible.

Necessity of Community Programs

For a community residence to be successful, there must be available community programs and services: employment, education, recreation, transportation, counseling, and recreation. The programs of all the homes in this study depended on community daytime activities. The implication is that in developing a community residence attention must be given to having a wide variety of community services available.

Transportation was of particular concern in all the homes since only in a few cases were residents able to drive and owned cars. Most of the homes owned their own vehicles or had arrangements for special transportation. Residents were also trained to use public transportation but often service is infrequent or inadequate.

Sense of Community

In all of the programs studied the sense of community was very evident. This was true for the large programs (Cheyenne Village and Community Living Project) as well as the small homes.

In the interest of meeting the "normalization principle," the goal of community residences frequently is "independent living" meaning living on one's own with ties to the community residence eventually severed. We wonder if such a goal misses an exciting opportunity of developing a social support network which the retarded person needs. Would it not be more useful to encourage former residents to maintain their social ties with the group home?

Learning about community may be one of the significant lessons of the community residence experience. It is part of the larger lesson that people who happen to be retarded are a part of the human condition, and they have something to contribute if we but have eyes to see it.

THE MANCHESTER GROUP HOME

An institution-sponsored group home for 12 men

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I. INTRODUCTION

As the policy of deinstitutionalization has taken hold, frequently parents and professionals in the retardation movement have become polarized. On the one hand are those who favor a community-based approach and point out the weaknesses and disabling affect of the institutions. On the other hand, the institution advocates claim that retarded people are protected in the institutions, that programming is more certain than in the community, and that new programs and techniques such as behavior modification are being used with effect. This debate has made it appear that there is an either/or choice between institutional and community-based approaches. Connecticut's Mansfield State Training School demonstrates that such a polarization is unnecessary. This state institution has become a leader in developing community residences while at the same time improving conditions at the institution.

Mansfield Training School opened its first community residence in 1964. Since then, ten more homes have been developed; and in 1973 the Connecticut legislature appropriated $1.6 million for Mansfield to open an additional 25 community residences. This case study describes how the program was developed and life in one of the residences.

II. DEVELOPMENT OF THE HOMES

The Mansfield State Training School

The Mansfield State Training School is one of two public institutions for the retarded in the State of Connecticut. Founded in 1818, it combined with the Connecticut Colony for Epileptics in 1917 and has since served as the hospital for the retarded, epileptic and blind people in Eastern Connecticut.

Mansfield, like the majority of other state institutions across the country, is a self-contained community. Tucked away in the rolling hills of rural Connecticut, its residents are largely forgotten by the general society. The self-containment of the institution is so complete that it even has its own fire trucks.

By 1964, when Francis Kelley was appointed superintendent, the resident population at Mansfield had grown to 2,000. He recognized that many people living at Mansfield could function well in the community, that community living would be a better life, and that it would probably be less costly than institutional care. He decided to move as many residents as possible to the community. The superintendent's views were aired to the President's Committee on Mental Retardation when in 1972 Mansfield was cited as an "island of excellence." Kelley said, "Parents like to think that institutions are okay. But no institution is okay including this one." To the President's Committee investigators he commented, "Look, it may seem like a country club, but it's still an institution. And an institution is an institution, especially with these huge old buildings we're stuck with. The idea is to get as many as we can into real life, or as close to it as possible."

The first group home was opened in 1964 in Hartford, some 20 miles from Mansfield. The administrative procedures established for the first home provided a model to be followed in later years. The home was leased from the owner on a 90-day self-renewing lease. The live-in houseparents and the relief house counselors were hired as Mansfield staff. In addition, a Mansfield-based social worker assisted the residents and the houseparents in day to day problems. The residents continued to be under the legal and administrative responsibility of the institution.

Sixteen mild and moderately retarded women moved to the new home and began their life in the community. The home was a success in that the women were able to work in sheltered employment, they liked the environment of the home better than the institution, and there were no overwhelming problems in supervising the home.

During the next nine years, a total of ten homes were opened at the rate of about one each year. Seven of the ten homes are operated by the Mansfield Training School, while three are privately operated. In these three privately operated homes, Mansfield pays a weekly room and board cost and assists the operator in establishing the home. The Mansfield administrators find they have less control over the operations of the home and the staff in the privately operated homes, and consequently prefer having the homes operated by Mansfield.

Originally, the group homes established by Mansfield were conceived as temporary homes for people who would eventually be able to live independently in the community. Therefore, only moderate and mildly retarded people who had the potential for employment and independent living were selected for the community homes. With these high-potential residents, the first two homes proved very successful. The residents were uniformly enthusiastic about living in the community rather than at the institution. Most of the residents increased in their ability to care for themselves and get around in the community. Furthermore, the residents did not get into trouble with authorities, or create other problems for the Mansfield administrators.

Because of the success of moving mildly and moderately retarded people to the community, in 1966 two homes were opened for men who were moderately to severely retarded. These men who had spent ten to twenty years in institutions could not function productively in a sheltered workshop and some had never developed intelligible speech. However, all were able to dress and undress themselves, control their bodily functions, and feed themselves. Unlike the first homes which were intended as transitional residences, the group homes for the more severely retarded are intended as permanent homes. Unless their abilities increase or substantially decrease, the residents will most probably be living in the group home for many years.

In 1969 a sheltered apartment residence was established as a transitional residence from the group homes to independent living. Twelve of the apartment units are for retarded men and women who are ready to live semi-independently, but not totally on their own. Two other units are for staff who assist the residents in day to day matters. Thus, Mansfield is developing a continuum of residential settings: group homes for more severely retarded people intended as permanent homes, homes developed as transitional residences, and sheltered apartments which are a prelude to independent living in the community.

Table 1

GROUP HOMES ESTABLISHED BY MANSFIELD TRAINING SCHOOL

	Location	Date Opened	Operator	Resident Level of Ability	Number of Residents
1.	Marshall Street, Hartford	1964	Mansfield	Mild-Moderate	16 women
2.	Lorraine Street, Hartford	1965	Mansfield	Mild-Moderate	12 men
3.	Gillette Street, Hartford	1966	Private	Moderate-Severe	16 men
4.	Prospect Street, West Hartford	1966	Private	Moderate-Severe	15 men
5.	Center Street, Manchester	1967	Mansfield	Mild-Moderate	10 men
6.	Collins Street, Hartford (apartments)	1969	Mansfield	Mild-Moderate	26 men and women
7.	Hamlin Street, Hartford	1970	Mansfield	Mild-Moderate	8 women
8.	Farmington, Hartford	1971	Private (church)	Moderate	24 men and women
9.	Enfield Street, Enfield	1973	Mansfield	Mild-Moderate	21 men
0.	Laurel Street, Hartford	1973	Mansfield	Mild-Moderate	10 men and women

Zoning

With the exception of one home in Hartford, the Mansfield program has not been faced with zoning disputes. Most of the homes are located in multi-family districts where boarding houses and similar group living arrangements are permitted. In Hartford, however, a group home was delayed because neighborhood opposition developed over similar homes for drug addicts and juvenile delinquents. This precipitated a review of the zoning regulations pertaining to "rehabilitation homes" by the city. After a long, drawnout review, the City Council decided to limit rehabilitation homes of all types to the two highest density districts. As a result, many potential homes in older neighborhoods with large, old houses are not available.

The Superintendent of Mansfield commented, "It's an old story. People agree with us that small group homes are better rehabilitation for the residents. Then they say, 'But don't put it in my neighborhood.'"

When Mansfield first started opening community homes, changing community attitudes was assumed to be impossible. More recently Mansfield administrators have found that it is possible to shape attitudes. In communities where a home is planned, the local planners and other city officials are contacted and the purposes and operations of the home explained. By working with local officials, it is often possible to develop enough support to overcome objections which might surface.

Community Programs: The Hartford Project

The Mansfield staff quickly recognized that the people they were placing in the community would require community programs in addition to their place of residence. Although there were sheltered workshops in the Hartford area, many of the people being placed in the group homes were unable to function productively in the workshops and were turned away. Yet they needed some type of daytime activity.

The Mansfield School, therefore, obtained a $50,000 HEW grant in 1967 to operate a Social Adjustment Project. The program, which came to be known as the Hartford Project, rented an unused hotel ballroom and converted it into a day activities center. A bus would pick up 40 group-home residents and bring them to the center where they would learn social skills such as grooming and getting around in the community. The emphasis was on using leisure time by teaching crafts, hobbies and games.

The Hartford Project also worked to develop skills necessary for employment in a sheltered workshop, and here the staff made discoveries. Many of the moderately and severely retarded people who had been called "unemployable" could in fact learn the skills and behavior necessary to

be employable by a sheltered workshop. Furthermore, the people who came to the project indicated they were very interested in working, particularly if they could receive pay.

By the third year, the Hartford Project had changed its approach. Rather than aiming at social growth and personal adjustment, the Project developed an employment program much like a sheltered workshop. Contracts for assembly work were obtained from local industries. Although the emphasis shifted, socialization and recreation were retained in the program. Each summer the Project hires a boat with income set aside from work contracts and takes a three-day sailing trip to Block Island. Throughout the year there are field trips and recreational programs. A social worker is on the staff full-time at the workshop to provide personal counseling to people at the workshop.

The work training approach for these "unemployable" retarded worked. By the summer of 1969, the Project had placed three people with Goodwill Industries, four in jobs in the community, and twelve with the sheltered workshop operated by the Hartford Association for Retarded Children.

When Federal funds lapsed in 1970, the program had proven itself well enough that the State of Connecticut agreed to underwrite the operation. Currently, the annual operating costs are approximately $150,000. Income from contracts is $50,000. The program has expanded so that 85 persons are now being served.

Additional Home Development

By 1973, nine years after the program of establishing community homes had started, there were 10 community residences: six Mansfield operated group homes, three privately operated homes with Mansfield clients, and the Mansfield operated sheltered apartments. A total of 136 men and women were living in these residences, and the resident population at Mansfield had dropped from 2,000 to approximately 1,400. However, to the administrators at Mansfield it remained clear that there were still many people living at the institution who could live in the community and would be better served by doing so.

However, to develop further community homes would require more funds and a stepped-up program. In May 1973, 55 state legislators from the Committee on Finance and the Committee on Corrections, Welfare and Humane Institutions visited Mansfield to get a first-hand look at the inadequacies of the institution. This was the largest delegation of legislators that had ever visited Mansfield, and they went away troubled about the conditions they saw. As a result of this visit and active lobbying by parents and the State Office of Mental Retardation, the Legislature approved funds for building new cottages at Mansfield as well as $1.6 million to open 25 new community homes.

Each of the new homes is expected to house 12 residents and a live-in staff of two. Staff support includes two relief houseparents and a social worker to assist the houseparents and the residents.

Of the 300 residents who will be living in the 25 new homes, some 50 will be severely and profoundly retarded. Mansfield has received a $90,000 Federal grant to provide special services and staff for the homes with these more handicapped people.

Changing Role for Mansfield

The program of community residences has shifted the role of Mansfield. By 1975 the resident population at the training center will drop to 1,000 or lower. Most of the people remaining will be severely and profoundly retarded, requiring extensive supervision and care. The training center will then have two key roles for its residents: (1) custodial care for those who are severely and profoundly handicapped, and (2) intensive education and training to prepare those with the potential for living in the community residences. For those people no longer living at Mansfield but still under its jurisdiction, the institution will have the responsibility of managing the community homes.

The change in Mansfield's role takes place at a time when Connecticut is shifting its approach to mental retardation. Until 1960, Connecticut, like most states, relied on large institutions to care for retarded people. To develop a more community-oriented program, twelve Regional Centers providing residential care as well as out-patient services were built. While smaller in size than the state institutions, the regional centers were themselves institutions with all the attendant problems. Recently Connecticut decided not to build any more regional centers which were residential institutions. Regional centers will continue to act as diagnosing, counseling, service and training centers. What residential facilities they operate would be small.

A second concept that is being encouraged by Connecticut's Office of Mental Retardation is using community services rather than developing specialized services for the retarded. According to the Commissioner of Mental Retardation, Garet Thorne, the regional centers have tended to become isolated from the community and need to be integrated into the community. The long-range goal is to have local communities accept responsibility for running programs for the handicapped, just like any other program.

The overall direction is the development of a community-based system of services, including residential services. What is unique about the Mansfield Training School is its active participation and leadership in the community-based approach.

III. THE MANCHESTER GROUP HOME

To the passerby there is nothing unusual about the large, stately house on East Center Street in Manchester, Connecticut that is a home for ten retarded men. Previously it had been the home of a local judge, but after his death it was vacant for four years. Now it has a new life.

The home was opened in April 1967, the fifth home developed by Mansfield. The three-story house is well suited to be a group home. There are five bedrooms for the residents, a comfortable living room, and a large kitchen and adjoining dining room. A basement room has been made into a recreational room with a pool table and television. The live-in houseparents have their own bedroom and living-room area.

The home is on a major road that once was lined with large homes of Manchester's gentry but is now giving way to motels, professional offices and shopping centers. But the feeling of a New England town is still there--the maple and elm trees along the streets, the white clapboard houses and neatly trimmed lawns. Downtown Manchester is a 15-minute walk away, and just up the street is a local shopping center and coffee shop where the residents sometimes go for a sandwich.

The Houseparents

The live-in houseparents are the major influence in establishing the style and social environment in the home. They have a variety of duties ranging from house management to bookkeeping to job finding. They prepare the menus for the home and order the food from the Mansfield Commisary which is delivered weekly. They prepare and serve the evening meal (the men make their own breakfasts and have lunch where they work).

The present houseparents, a couple in their fifties, have worked at the home for three years. The housemother, who previously did clerical work for an insurance company, heard about the job from her cousin who was the former houseparent. She had no previous experience working with retarded people and learned on the job with assistance from the former houseparent. The housemother is an employee of Mansfield with the classification of Mental Retardation Aide II who receives between $7,000 and $8,500 per year. The housefather had previously worked as a custodian in a local manufacturing firm. He has recently been hired as an Aide I ($6,000-$7,200 per year).

Their greatest influence is in managing the house and supervising the residents. As the housemother puts it, "I make sure the boys look all right--that they dress properly and use clean clothes. I also make

sure they get to work on time. One boy, for instance, doesn't have a sense of time or money. I have to make sure he gets up at the right time. One night he went to work at three in the morning and just stood waiting for the bus because he didn't know what time it was."

Each week, the men give the housemother their pay which she records and in turn pays their bills, including room and board payment which varies according to the income of the resident. Each resident gets $10 a week spending money and another $10 is put in a savings account.

The houseparents also help the residents do major shopping for themselves. Residents buy their own clothes, but the housemother comments, "For shoes I like to go with them." The housefather, in another instance, helped one of the residents buy a television set on time and to work out the payments.

A vital area of support by the houseparents is in finding jobs for the men. If one of the residents needs a job, the houseparents will scan the newspaper want ads, set up employment interviews and drive them to appointments. For one of the residents, the housefather called a friend who owned a restaurant and got a dishwashing job. The houseparents also help the men keep their jobs by ironing out problems that arise on the job or negotiating differences between employers and the men.

Although officially the houseparents are "on duty" from 3:00 p.m. to 11:00 p.m., in fact they make themselves available 24 hours a day since they live in the home. They have a separate bedroom and their own living room which is a converted sunporch off the large, main living room. Although they are in the same house constantly (except for the time away from the home during their two relief days each week), the houseparents keep themselves somewhat apart from the retarded residents. They take their meals separately in an alcove off the kitchen, while the residents eat in the dining room. In the evening they spend time in their living room, generally watching television. The relationship between houseparents and residents in the Manchester home is friendly although the houseparents maintain clear authority. Residents call the houseparents "Mother" and "Father" while the houseparents address the residents by their first names.

The houseparents exercise considerable control over the lives of the men. They set and interpret the rules of the house. Whenever entering or leaving the house the residents must let the houseparents know. Although they may go out at night and do as they please, residents must be in by 10:00 p.m. (11:00 p.m. on Saturday) and they have to let the houseparents know where they are going. The men are not permitted to eat in the basement recreation room or in their rooms. Smoking is allowed, but not in the bedrooms. No liquor or beer is permitted in the home, although the men occasionally stop in at local

bars, and nothing is said. They are not permitted to go in another person's room without permission, apparently to avoid possible thefts and disputes over privacy. Entertaining women above the first floor is not permitted. Use of the telephone is limited to business calls and three minutes for local calls. If a resident wishes to call a friend or his family long distance, he uses the public phone in the nearby shopping center.

On the rare occasions when a man breaks the rules or otherwise acts inappropriately as judged by the houseparents, then the houseparents restrict him. For example, the housemother commented, "If the boys disobey, then I restrict them. I tell them they can't go out at night for a week. This works best and they obey next time."

The houseparents display a genuine liking and concern for the residents. The housemother is particularly sensitive to the moods and needs of the residents and often will sit down with them and discuss problems. One evening one of the residents came home in a grouchy mood, having worked hard all day. When he grumped at another resident, the housemother quietly let the others know that they should leave him alone. Then, in a motherly gesture, she brought him a piece of pie and said a few gentle words to him.

Although Mansfield has an organized leisure time program for the residents, the houseparents will often carry out their own activities with the men: trips to concerts, local parades and civic events and picnics. Many times when there are only a few men home for supper they will all go out to dinner together.

The housemother finds her biggest management problem to be the way in which the retarded men will "make little problems big things." What to a normal person might be a minor irritation, to one of the residents becomes a major, overwhelming difficulty consuming their attention and energy. These situations require patience and concern to put the matter into perspective.

The Residents and Their Lives

The ten men who live at the East Center Street home are an unlikely grouping. Their common characteristic is that they are mentally retarded, but otherwise they differ considerably. The men range in age from 19 to to 52 with a median age of 33. Four of them have never lived in institutions and came directly to the home from the homes of their parents or foster parents. However, the other six residents have spent long periods of their lives in institutions--from 6 to 36 years. One was admitted to Mansfield at the age of 9 and lived there until he was thirty when he was placed in the home. Another resident, age 45, was placed in an institution at the age of 6 and came to the home at the

age of 42. The average length of stay in an institution is 18½ years. Seven of the residents have lived at East Center Street for three to four years, with the average length of stay being 2.8 years.

All of the residents are either mildly or moderately retarded. Although one is blind and another has epileptic seizures, all of them are able to care for themselves, get around in the community and hold jobs.

A typical day at East Center Street begins at 7:00 a.m. when alarm clocks go off and the men arouse themselves, wash, get dressed and make their beds. Breakfast is prepared individually by each person. On a typical morning, Alden sits drinking coffee, listening to his pocket radio, and munching on nuts. The housefather teases him: "You'll be nutty if you only eat nuts." Another resident puts on bacon and then discovers that there are no more eggs in the refrigerator. He goes to the basement to get another dozen from storage. In the meantime, his bacon starts to burn and the housefather turns down the heat. The resident cooks up the eggs and sits down to eat his breakfast. Another resident comes down. "How's it going, Charlie?" There is some good natured teasing as each prepares his breakfast and sets off for work.

Seven of the residents have competitive employment in the local community. One resident has been working for three years as a janitor at a local textile mill; another works as a sandblaster at a nearby teflon manufacturing company earning $100 a week; another resident had worked and lived on a chicken farm but there was insufficient support for him and he got into arguments with his boss. He and another resident work at a local restaurant as busboys. Another resident has had difficulty staying in a job because, according to the housemother, "He is very slow and stubborn." He now earns $2.00 an hour at a McDonald's hamburger restaurant cleaning up trash. Two others attend the local sheltered workshop although there are some hard feelings on the part of the local association for the retarded that the Mansfield school is placing "Mansfield people" in their workshop. Recently the local ARC established a rule that only people whose parents live in Manchester may be hired by the workshop. However, those living outside Manchester may be accepted for evaluation.

Between three and five o'clock, residents begin to return from their jobs. As they come in, they each check in with the houseparents and get ready for supper. The evening meal is prepared by the houseparents. The housemother serves each a plate from the stove, because "otherwise they may not all get equal shares."

The evening meal is one of the few times most of the residents are together since their work schedules vary considerably. Conversation around the table often is about the work they have been doing. On one evening, talk drifts to the subject of alcohol. "When I was at home, I came in and my brother offered me a beer and I drank it." The others

chimed in with their stories of drinking: how they liked it, how it was a bit risque and adventuresome, what it felt like.

After dinner, each takes his plate into the kitchen where the one with clean-up duties stacks the dishes in the dishwasher. In the evenings, the men often watch television--one of their favorite leisure activities. The house is well stocked with televisions, radios and record players. In addition to the house set, several of the men own their own television sets. Indeed some of the bedrooms have two sets. In the basement is a billiard table which the men enjoy. Much leisure time is spent socializing with each other. Among the men there are strong friendships, and they seem to genuinely enjoy each other's company.

There is also an active leisure-time program worked out by the Mansfield staff. On Tuesday nights a special education teacher from the local school district comes to the house to teach reading. On Wednesday night there is a young adults club. Thursday nights a bus from Mansfield provides transportation to a church in downtown Hartford where the Hartford ARC provides a weekly recreation night for retarded people. The residents can see a movie, take part in a dance, or take a cooking or arts and crafts class.

The Thursday night social evening provides a way for the men to see friends who live in other houses in the Hartford area. One young resident particularly likes to go because he can see his girlfriend who lives in another community home. They want to get married, although they are unclear how they will support themselves. His comment about finances is, "Well, I have $250 in the bank and I save $10 a week."

The Mansfield recreation coordinator also programs weekend activities such as trips to county fairs, baseball games, and picnics. As with all the activities, they are voluntary and done as a group.

Some of the residents are also involved in the community on their own. One is in a barbershop quartet; another is in a boy scout troop and is an usher at the local church; and another attends evening high school.

Without exception, the residents prefer life in the Manchester group home to living in the institution. They enjoy the greater freedom they have and the privacy of the home. Having a job and receiving pay is also highly rewarding. Although they do not have a great deal of spending money, they are able to save their money to buy television sets, record players, clothes, and presents for others.

Social Worker

Once a week the social worker from Mansfield comes to the house to consult with the housemother about the residents and work out any problems that arise. The social worker is the major decision maker about the placement of each resident. When she senses they are ready for movement to a sheltered apartment, she discusses the move with them. The social worker and the houseparents work together to find employment and work out problems employers have with the residents. The social worker also assists residents in relationships with their families.

Finances

The East Center Street home is leased by Mansfield and operated as an extension of the school. Total annual operating costs in 1973-1974 were $30,828, with staff costs accounting for 43 percent of the costs (See Table 2). The costs were offset by income paid by the residents for room and board, however, this is paid directly to the state and was not accounted. The cost per resident per year is $3,083 compared to the annual cost for residents on the Mansfield campus of $6,500 per year.

Although the time devoted by the social worker is allocated to the home, there are some overhead costs which are not included. These are the administrative costs of the social services section, which manages the community residence program, leisure-time programming, and transportation provided for the weekly social gatherings. Other costs not included are for medical care (covered under the state program for the medically indigent) and the sheltered workshop.

Table 2

Annual Costs of Manchester Home

(July 1, 1972 - June 30, 1975)

Housing		
Rent	$ 6,300	
Utilities	2,634	
		$ 8,934
Food	$ 5,007	$ 5,007
Personnel		
Staff salaries	$13,487	
Social worker time	3,000	
		$16,487
Miscellaneous	$ 400	$ 400
TOTAL		$30,828*
Cost per resident per year		$ 3,083
Cost per resident per week		$ 59.29

*Note: Resident payments for room and board are based on resident income. These payments are paid directly to the State Finance Department and were not accounted. However, in 1973 the payments amounted to $6,872. The net cost of the Manchester Home is therefore less than the total indicated.

IV. OBSERVATIONS

The Institution's Role in a Community Based Approach

The community residences established by Mansfield illustrate how an institution can take the lead in providing for retarded people in the community. Mansfield's experience suggests that there does not have to be a polarization between those who defend the institutions and those who favor a community based approach. Rather, Mansfield has been one of many organizations providing services in the community for those people who are better served in a community setting.

In developing group homes, Mansfield has several advantages:

1. The administrative experience of the training school can be applied to developing homes. Furthermore, the political weight of the institution can be used to obtain continued or new funding.

2. Because it is a relatively permanent organization, the institution can assume long-term responsibility for the retarded person. This can help alleviate one of the greatest fears and concerns that parents have: what will happen to their child when they die or can no longer care for him.

3. There is a single organization responsible for continuing quality in the homes which can be held accountable.

4. Support services of the institution can assist the home in areas ranging from diagnostic and evaluation services to transportation.

There are also potential disadvantages in having an institution develop community residences. Perhaps the greatest reservation is that the inhibiting attitudes, style and "culture" of the institution will be extended to the community residences. At the Mansfield homes, for example, the practice of referring to the adult residents as "boys and girls" continues in the community homes as it does in the institution.

However, several steps have been taken to prevent harmful institutional practices being extended to the homes. The Community Services Division which administers the program is separate from the division which operates the training school, reporting directly to the Superintendent. Furthermore, there has been a conscious effort to avoid red tape. Administration is informal rather than formal (intentionally there are no written administrative regulations for the home), and houseparents are allowed to operate with a relatively free hand as fits the situation and their personal styles.

Another potential disadvantage is the limited community support of the homes. The 10 homes developed by Mansfield have a single base of support--the institution. None of the homes have advisory or governing boards from the professions, the community or the parents. As a result, there is absent the leavening influence as well as support which an advisory board might provide. This does not appear to be a major problem, although there are some situations which might be avoided or worked out if there were more community involvement. For example, in Manchester the ARC-operated sheltered workshop has a policy that only Manchester residents may attend the workshop. (East Center Street residents are not considered Manchester residents since their parents do not reside in Manchester).

In general, there has been cooperation with community organizations. For example, the Hartford ARC operates the Thursday night recreation program.

The Need for Supporting Community Programs

It did not take long after the first community residence was established to realize that providing a home in the community was not enough. If life was to be better in the community, adequate programs were needed. The Hartford Project was started by Mansfield because of the lack of available daytime programs for those unable to work. Mansfield now has a leisure-time coordinator who schedules activities for weekends, and there is a once-a-week social evening.

Furthermore, there are other community programs which the residents are involved in: sheltered workshops, the Boy Scouts, church, and adult education classes.

The objective of Connecticut's Commissioner of Mental Retardation is that local communities provide generic services such as recreation, education, and vocational training, just as they now provide such services for normal people. The state would often have to initiate programs, just as Mansfield had to start the Hartford Project. However, the program would be transferred eventually to the community, which would come to view the program as a natural part of the programs provided for its citizens. Such an approach requires a high degree of community participation in the programming.

The point is that retarded people, like the rest of us, need more than just residential services. Providing a roof is just the beginning of establishing a community residence. Educational, vocational, health, leisure-time and other services are needed too.

The Problem of Maintaining Quality

"There's no point in moving people from some big, bad institution into some little, bad foster home." This comment by Mansfield's Superintendent summarizes a fear that parents and professionals have about the development of community homes: namely that the quality in the homes may deteriorate.

What mechanism can be devised to assure quality is maintained? The Mansfield method is to operate the homes and have a social worker make weekly visits. Other homes have parent/professional boards, and a few places have residents participating in house management. Licensing agencies potentially could play a role, but usually limit their interests to physical features of the home.

In the challenge of establishing a group home, the question of assuring continuing quality is often overlooked (or taken for granted). As the number of community residences increases, this matter will become of increasing importance.

The Influence of the Houseparents

At the Manchester Home, as in all the homes studied, the houseparents have substantial influence in setting the tone and social environment of the home.

The Manchester houseparents have established themselves in the role of benevolent protectors. Their concern and caring for the residents is strongly evident. Yet the effect of many of the rules and customs of the home, while well intentioned, is to limit the ability of the residents to experience areas of life which they need to learn if they are to be able to live independently.

Nevertheless, all the residents like the Manchester home above living in the institution. Their range of freedom is much greater; their ability to develop personal skills is greatly enhanced; and, perhaps most welcome to the residents, they can work and receive pay. They enjoy the home itself--the opportunity to eat in a small dining room, to poke around in the refrigerator for a snack, to have privacy and possessions, and a group of friends. From their point of view, the community residence program is providing them a sheltered residence by far more acceptable and fulfilling than life in the institution.

B.

LUPINE HOUSE

A parent-originated community residence for 6 young women

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I. INTRODUCTION

In 1969, a group of parents came together to organize a group home for their mildly retarded daughters. All the parents felt that their daughters, in their late teens and living at home, needed a more independent life of their own. The parents were also concerned about the time when they would no longer be able to care for their daughters, so they wanted a permanent place for them. Later they realized their daughters could learn how to live independently.

Within a year the parents had found a house and selected a housemother and a full complement of six residents. They had also cleared the hurdles of zoning and licensing regulations and financing.

In the development and operation of Lupine House,* the organizers have aimed for a "normalized" style. Everything is planned to encourage the young women to function as adults in a safe, comfortable, and happy place. The home is a large, comfortable private house in a woodsy, family neighborhood of a small suburban town in the San Francisco Bay Area. During the day all of the women go to work. Two commute by bus to the city where they have "normal" jobs. Two go to vocational training programs, and two work at a sheltered workshop. Four of the women also attend basic reading and math courses at a nearby junior college.

With the assistance of a housemother, the women do all the housework. The housemother uses cooking, shopping, and cleaning chores as means for teaching living skills. Each woman can decorate her own room, have a key to the front door, and use the telephone--all normalizing features of the home.

In successfully setting up the house, the originating group has shown how concerned parents can overcome technical problems and community opposition. And in the style of the home environment they have created, the house initiators have shown how to balance independence and safety for their daughters with security for the parents.

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*To preserve the privacy of the residents, the name of the home and the people involved have been changed.

II. HISTORY AND DEVELOPMENT

Starting Out

The two mothers who originated the idea for the house had first gotten to know each other in the mid-1950's when they worked together to organize a nursery school for their retarded daughters. When their children were in their late teens they had attended special education classes all day but were still living at home.

As their daughters approached the age when they would no longer be going to school, the mothers talked frequently about finding a place where their daughters could live away from home with other young women like themselves. Both mothers believed that continuing to live at home would inhibit their children's social development. And they also saw that their daughters were isolated and had few friends.

The two mothers began to visit group homes in the Bay Area. There were none in their own community, and one which they liked in a nearby community, did not have space available.

But one of the daughters, who had been with her mother on some of the visits, became excited about the prospect of living away from home. Although there was no place that seemed quite right to either of them, she began to encourage her mother to find a suitable place where she could live more independently.

The House

About that time one of the mothers learned of a five bedroom house that would soon be available for rent. It was this house--the right size in the right place--that became Lupine House, a home for six retarded young women.

Surrounded by trees on a steep hillside, Lupine House looks like any other house on the narrow street. The wood and stucco house was built for a single family in the late 1940's. It had ample space for a small group home: a living room for lounging and talk, a family room with a television and ping pong table, and even a separate dining room.

Off the large kitchen there is a utility room with a washer and drier which the women use to do their own laundry. On the second floor are five bedrooms, each decorated by its occupant. Two of the women have their own bedrooms while four double up. There is a separate bedroom and bath for the exclusive use of the housemother. The one remaining bath is used by all six women who have had to work out a schedule to avoid traffic jams.

The home's only unusual features are smoke detectors and a fire alarm, which were installed in the hope that the state licensing agency would relax its requirement of 24 hour supervision.

Although the town center is only half a mile away, one has the feeling of being in the country since the houses are built on large lots on steep hillsides. From the house the women can take a path down the hill where the public bus stops. Downtown San Francisco is forty-five minutes away by commuter bus. It is a ten minute bus ride to the local junior college where four of the women are taking remedial reading and math courses.

The town is a small, growing community of upper middle class suburbanites. In 1972 the population was 13,500. Between 1960 and 1970 the population increased 87 percent. The median family income in 1969 was $16,397 with half of those who worked commuting to San Francisco. The community is very much like the nearby communities where the women grew up and lived before they moved to Lupine House.

Another couple who had a retarded daughter, Donna, in her mid-teens, was invited to join in. Each of the three couples put up fifty dollars to get things started. One mother, who had run a small business with her husband, volunteered to do the administrative work necessary to get the home started. The planning committee was expanded to include two other couples whose daughters were also applicants for the home, and a social worker who worked with the mentally retarded.

The house had been painted and repaired by the owner, but the group was faced with a number of obstacles before the young women could move in. The first was the cost of remodelling the home to meet fire, building and zoning codes. The town administration was friendly to the idea of a group home, but the house would have to meet code requirements. An additional stairway for a fire escape would have to be added in addition to having an offstreet parking area built.

To pay for these required changes and for the furniture that was needed, the group of parents turned to a local community foundation. One of the parents in the organizing group discussed their needs with the executive director of the foundation whom he knew. An application was submitted and $5,000 was awarded for the improvements.

Zoning

A thornier problem was zoning approval. The group, now calling itself officially the Parents Committee for Lupine House, wrote the city's Planning Department for approval for opening the home in a residential neighborhood. The letter explained: "We feel that given the opportunity to live in an atmosphere designed to combine the quality

of home life with the benefits of group life and to have an adequate adulthood away from the family, these girls will find opportunities for growth and for making their own contribution to the community."

The professionals in the Planning Department were sympathetic to the purpose of the home, but the city's zoning code did not provide for such uses in residential neighborhoods. The idea of a residence home had simply not been thought of at the time the code had been written.

In a report to the Planning Commission the planners expressed the opinion that the proposed home would be "not detrimental to the public interest,...in accordance with the purposes of the district, and...of the same basic characteristics of uses already permitted." The Planning Department staff recommended that the Planning Commission change the code to allow "homes for exceptional children" in single family districts and that Lupine House be allowed as a permitted use. (This meant that, in the future, the Planning Commission would be required to review each application for a similar home.)

The Planning Commission approved the Staff's recommendation without dissent or controversy. But, in the week before the City Council took up the matter, a group of property owners in the neighborhood of the proposed home collected 105 signatures in opposition to Lupine House. Alerted by a City Hall staff person to the growing opposition, the parents asked friends to come to a City Council meeting to speak on their behalf.

On the night of the hearing, the nervous parents were astonished to find the City Council chambers packed with people, both friends and foes, as it turned out.

One of the parents spoke first: "On the whole they are lovely citizens,.... They need a home atmosphere where they can do their own thing. They can become part of the community only if they can live within the community."

A member of the opposition argued vehemently that approval "would remove another brick from the buttress that fortifies single family zoning." Other opponents implied that the young women would be dangerous and would have a bad influence on neighborhood children. Some argued that property values in the area would be lowered.

In an effort to gain support from other homeowners, one speaker said, "If this home opens it would pave the way for other, older areas in the community to become a mecca for semi-institutionalized groups."

A parent argued, "If a child such as mine were not in a place where she could lead a sheltered life, making her own decisions and making her own mistakes, she would cost the taxpayer $250,000 in her lifetime."

A neighbor, who was a teacher of retarded children, told the councilmen, "When people talk too much about the zoning laws and not enough about people, I get worried." Unexpected allies, including a physician who lived in the Lupine House area, spoke out in favor of the home.

One of the councilmen who had a retarded daughter living in a state institution asked the city attorney if he should abstain from voting on the issue, but no, he could participate in the debate and vote. The councilman made a strong plea for Lupine House.

After an hour and a half of discussion, the vote was taken. Lupine House won--three to one.

Immediately after the stormy City Council meeting, a city employee warned one of the parents: "I would strongly suggest that little or no newspaper publicity be given to this project for at least four to six months. This is a local election year and this could be political dynamite."

But no one took advantage of the issue and, after the council decision, the issue subsided. Lupine House has never experienced any harrassment from those who spoke strongly in opposition. To follow-up, the Parents' Committee sent letters to each individual who spoke before the City Council, those opposed as well as those in favor. The letters further explained what Lupine House was and assured that the women would be good neighbors.

Sometime later, after meeting and living next door to the residents of Lupine House, an elderly woman who had been one of the leaders of the opposition, became a firm friend of the house. She even volunteered to write a letter of support when the Lupine House Board decided to open a similar home in a nearby community.

Sponsorship

The third step before Lupine House could open was to obtain the legal sponsorship of the local Association for Retarded Children. Sponsorship by the ARC, a non-profit, tax-exempt organization, would allow Lupine House to receive charitable gifts and grants from individual foundations. More importantly, the organization's backing would ensure the continued existence of Lupine House, even after the original group of parents had died or were no longer able to take care of their children.

But the local ARC was hesitant about sponsoring a new and untried kind of project like Lupine House. The Association, which was small and had little experience in operating programs, was particularly reticent since they had recently expended considerable time and energy in opening a respite home.

The organizers of Lupine House stressed that their plan was for the home to be financially self-sufficient. Lupine House asked for $1,500 of an ARC fund established for community residential services, but no on-going financial support would be necessary.

The ARC Board put off making a decision until one mother, who had been a charter member of the ARC and President of the local chapter a few years before, put it on the line. What was the ARC for, she argued, if it wasn't to help establish services for their children? She reminded them that she had put a lot of work into the organization and that she wanted the support of the ARC Board in return.

Lupine House became an official division of the ARC. A contract was drawn that ensured the ARC's continuing support, but without major financial obligations.

Licensing

One of the early volunteer supporters on the Parents Committee was an experienced social worker. With her help, the Lupine House parents avoided problems with licensing. On her advice, they applied for a license as a family care home limited to six residents.

In inspections following the opening of the house, the county licensing agency also came up with minor but irritating requirements. A thermometer would be needed for the refrigerator, for example, and a doctor's prescription would be necessary for residents to drink skim rather than whole milk. This caused some friction between the housemother and some of the women who could not understand why they had to get their doctors to write prescriptions for milk.

An even more troublesome issue has been the state requirement that there must be a staff person present whenever there is a resident in the home. The housemother's hours are from 3:30 p.m. until 9 a.m. the next day planned around the women's daytime jobs or sheltered workshop activities. So usually there is no supervision problem. But occasionally there are times when the workshop is closed or one of the women is unable to go to work. Then, although the women, parents and administrator of Lupine House all believe that the residents are capable of taking care of themselves, the state licensing agency requires a supervisor.

As one parent put it, "My daughter can take the public bus to the workshop, walk to the shopping center to do some shopping, but then she has to sit in the public library because the rules say she can't go home if the housemother isn't there." When the parents went to the head of the state's Bureau of Developmental Disabilities, he agreed that the licensing requirement needed to be more flexible. But the intermediate administrators have not yet found a way to respond and the problem remains unsolved and a source of exasperation.

Selecting the Housemothers

The first decision that the Parent's Committee made in the crucial process of selecting staff for Lupine House was that there should be a single housemother or counselor. Paying the salary of only one full-time staffer would be less expensive but, more importantly, hiring a husband and wife team might reinforce the tendency of the residents to see themselves as children in a family. The parents also thought that it would be an emotional strain for a couple if the husband were the only man in a house of seven women.

The volunteer administrator placed ads in the local newspaper, and contacted a local employment service and social welfare agency. After she did preliminary screening, a committee made up of a parent, the social worker, and the administrator interviewed the applicants.

They selected Rachel, a forty-year-old formerly married woman with two grown children. She had some experience in special education, expressed warmth, and seemed mature from her experience as a mother.

Rachel's hours were from 3:30 in the afternoon until the residents left for work or school in the morning, at 8:30 or 9:00. She would work on either Saturday or Sunday and have two days off each week. She was paid $325 a month, plus room and board. The parents recognized that this was low pay, but a higher salary would have raised the costs of the house to a level they couldn't afford.

The housemother moved all her belongings and made Lupine House her home. Looking back, the administrator believes that this is not a good idea because it ties the housemother too closely to the home. Rachel was unable to have a life of her own apart from Lupine House. Her personality and her possessions were completely integrated into the Lupine House life and, when she decided to leave 18 months later, it was quite upsetting to the residents.

Rachel's relationship to the women was warm and motherly. She acted as if they were all part of a family, and initiated a lot of hugging and touching. At the time, the parents and four of the young women responded favorably to Rachel's maternal approach. But two of the women did not appreciate the mothering. Gladys felt she needed independence more than another family.

Although Rachel had created a warm atmosphere and had worked out the early problems, she decided to leave in January 1972 after a year and a half, to return to school. The housemother's job had been emotionally draining and living in the house had limited her own social life.

Although the Lupine House Board was sorry to see Rachel leave, they were grateful to her for providing stability in the important beginning period of the home.

The second housemother chosen was Jolene, aged 35, who was studying for a master's degree in recreational therapy at a local university. She was single and had worked with physically handicapped people and minority groups. Unlike Rachel, who was outgoing, Jolene was quiet and took longer to get to know the women at Lupine House. Nonetheless, she had common sense and warmth and within a few months she had gained the confidence of the women.

Rather than being a mother, Jolene chose to be a helper, instructor and arbitrator at Lupine House. The administrator observed, "Jolene treated the young women as individuals, and she was sensitive to their needs to mature and develop. One example was when she encouraged Linda and Gladys in their special Olympic swimming, which had come to mean so much to them." The administrator encouraged Jolene to have a place of her own outside Lupine House.

Jolene remained as housemother for 18 months. She, too, left because she wanted more time for her private life and a larger salary.

For the three months that followed, Lupine House went through an unsettled period with no permanent housemother. It was a particularly hard time for the residents. Although the administrator warned them not to become attached to the temporary housemothers, affectionate bonds were formed with an older woman who worked at the home for a few weeks, and with others who had even shorter stays. Sadly, the young women hung out a "Welcome" sign for another new housemother who decided at the last minute not to take the job. While the women were somewhat shaken and found it difficult to be patient, they managed to survive the difficulties.

At last in August 1973 the selection committee chose Paula, a 26-year-old woman who had been a physical education teacher in Montana and had worked at a local blood bank since coming to the Bay Area. Paula, who like Jolene, seems reserved, sees her role as that of helping the residents to be more independent. She is a friend, as well as teacher and enforcer of the rules. Her job requires considerable skill at interpersonal relations and sensitivity to potentially upsetting situations.

After three years of experience with houseparents, the founders of Lupine house have drawn several conclusions. First, they don't expect a housemother to stay for more than two years. The position is often appealing to a qualified person during an interval in her life when a single life, low pay, and restrictions on mobility and free time are acceptable. The administrator is presently considering changing the work week to a four days on, three days off schedule to make it easier on the personal life of the housemother.

Second, they have found that it is more appropriate to the goals of Lupine House for a housemother to serve as a counselor and manager rather than as a mother. The goal is for the women to learn to take care of themselves. Thus, the mother-child role relationships are de-emphasized.

Third, it is necessary for a housemother to be well-organized (since she manages the household), confident (since the women often challenge the housemother), and energetic (because the work is physically demanding), in addition to having the more obviously necessary qualities of compassion and understanding. Interestingly, previous experience with retarded people does not seem to be of particular importance. None of the houseparents selected had formal training in working with the retarded, yet each was considered a good houseparent in her own way. Also the Lupine House organizers found that a reserved personality was no barrier to success. Both outgoing and shy women were successful. Genuine caring and concern for the women seems to be the single most important trait regardless of personality type.

Administration

Although Lupine House was started by a parents committee, an Operating Board was formed after the home was in operation, and the membership was expanded. The by-laws for the fifteen-member Operating Board limits parents to a maximum of four positions specifically to avoid making the policies of the home too protective. While the home is a division of the local ARC, the ARC Board of Directors has little to do with the policy at Lupine House. Only three of the Board members are from the ARC. Five other Board members are interested citizens, and four are professionals in the field of mental retardation--a social worker, a teacher of mentally retarded children, a special education teacher in public school, and an administrator of the State Department of Rehabilitation.

Initially the Board addressed many operating details of Lupine House, but the focus has since changed. Now the Operating Board is largely concerned with policy-making issues such as the nature and direction of expanded services.

A Professional Advisory Committee was also formed. It consists of two doctors, a guidance consultant, the coordinator of programs for the mentally retarded in the county schools, and a social worker who is a consultant to the house. The Professional Advisory Committee is supposed to advise the Operating Board on admission, program evaluation, retention and discharge of residents, and parents' appeals. However, in practice the Committee has met only once. The administrator has consulted individually with members of the Committee in specific matters, so the Committee serves more as a technical resource pool than an advisory committee.

The major policy-making sources are the housemother and the administrator who make the day-to-day decisions. For the first two years of operation the administrator was a volunteer parent. However, with the decision to open a second home, Magnolia House, and consideration of expanding into sheltered apartments for "graduates" of Lupine House, the need to pay the administrator for her time became apparent. A grant

from a local foundation was obtained in order to open Magnolia House and to pay the administrator. The hope is that the administrator can later be paid out of operating funds from the expanded operation.

The Policy Manual

In order to bring together the policies and organization of the home, the Board decided to prepare a policy manual. Several of the Board members felt such formality was unnecessary. After all, Lupine House was a small operation and they all knew each other and everyone would act in good faith. Why go to the trouble?

However, several Board members urged that it would be worth the time --that it would clarify their positions in the process and provide consistency in carrying out policy. These arguments proved correct. The manual, since it was prepared, has been used over and over again. The administrator said: "It's surprising how often we do refer to it."

Writing the manual took over a year. It included a description of how the house was organized, and a careful delineation of house operating policy. The broad philosophy is the now familiar one of "normalization." Specifically, this means to the Lupine House Board training leading to independent living.

Examples of policies outlined in the manual are:

Intake--outlines a procedure in which the house social worker and administrator review applications before there is an interview with the Operating Board's Admissions Committee.

Personnel--describes the job requirements and qualifications for the housemother, and terms of employment such as holidays, resignation, and evaluation.

Hiring Procedure--describes a process of recruitment, interviewing and selection.

Grievances--describes how grievances should be first worked out with the administrator and/or social worker, and then referred to the Operating Board if they cannot be resolved.

Financing

The Lupine House budget for 1974 is $31,989--or a yearly cost per resident of $5,331.50. The largest expenditure, $19,299 or 60 percent,

goes for house supervision. This includes salaries for the housemother and relief housemother, half-time pay for the administrator, and about $500 worth of administrative services from the local ARC. (See Table 1 for detailed listing.)

The second highest expenditure--$6,740--is for rent and other house expenses such as utilities and phone. Food costs come next at $4,500, followed by $850 for transportation (including maintenance for the house 12 passenger van), and $300 for entertainment and education expenses.

Funding Sources

The monthly per person cost of $445 is met in a variety of ways. Three of the women receive Supplemental Security Income (SSI) payments of $250 a month from the Federal government. Two others pay $250 a month from a combination of their own wages and Social Security payments. For these five there is a supplemental payment by the County Mental Health Center of $171 per person per month under California's Short-Doyle law. The sixth resident is totally self-supporting and pays $275 a month from her salary.

The total monthly income from these sources is $2,380 leaving a deficit of $390. The Board is considering asking parents to contribute $25 a month, leaving a deficit of only $240, which could be met from fund raising and other contributions.

The financial situation at Lupine House has never been static. When the house first opened in 1970, parents made up the entire difference between what was available from public assistance support and the actual costs. As the residents began earning wages, they contributed to their housing costs. In November, 1973, the Community Mental Health support of $171 per month began. But these state supplementary funds are not assured and, if there are state fund cutbacks, the parents will again have to provide the difference between expenses and the income from SSI payments.

When Lupine House was first starting, cash was needed for home improvements, furnishings, the first month's rent and other initial costs, such as licenses. Before the house opened, the parents put up $50 each as a sign of commitment. As the opening came closer, they also donated both furniture and funds.

The local ARC had been given a bequest for the development of community residences, of which $1,500 was made available to Lupine House. One of the grandparents of a woman who was going to live in the home also helped at the outset by donating $500 for the first month's rent and expenses.

However, the largest initial contribution was from the San Francisco Foundation which provided $5,000 for the improvements required to meet the conditions for the Use Permit. (The San Francisco Foundation is a 25 year

Table 1

Lupine House 1974 Estimated Budget

Housing		
Rent	$ 4,260	
Utilities	1,280	
Insurance	300	
Building maintenance	500	
Equipment maintenance	150	
Telephones	250	
		$ 6,740
House Supervision and Management		
Housemother and relief	$10,705	
Administrator (1/2 time)	5,000	
Staff benefits (15%)	2,356	
Workman's compensation	60	
Accounting services	75	
Licenses	85	
Publicity, advertising	75	
Office supplies and postage	50	
MARC administrative services (estimated value)	493	
Equipment, furnishings	400	
		$19,299
Transportation		
Maintenance and gas, house owned vehicle	$ 500	
Insurance	300	
Reimbursement for local travel	50	
		$ 850
Food/Household Supplies		$ 4,500
Entertainment/Education		$ 300
Miscellaneous		$ 300
TOTAL		$31,989
Cost per resident per year		$ 5,331.50
Cost per resident per month		$ 444.60

Old organization with annual grants of $3 million.) More recently the Foundation provided a $36,000 grant for opening a second home and paying the administrator's salary for two years.

Lupine House has been aiming for financial self-sufficiency using the residents' own wages and public funds. One factor in making this goal seem possible has been the stability of the home's expenses. Operating expenses have stayed about the same, even in the inflationary period of the early 70's. Expenses took a slight jump in 1974 with a rise in salaries of the housemothers and an increase in the rent from $325 to $390. However, the parents, who provided the financial support needed at the start of the program still must act as financial back-stopping. The prospect for long-range financial security for their children is improved but not yet assured.

Further Developments

After two years of success with Lupine House, the Operating Board decided to take on a greater challenge--a second home for six women who were moderately rather than only mildly retarded. A more structured daily program would be required, with 24-hour supervision by two housemothers.

It is hoped that the second home, like Lupine House, will be a first step to independent living. A woman who has increased her ability to care for herself while at the new house will have the option of moving to Lupine House when a place is available.

After finding a suitable large tract home in another suburban community not far from Lupine House, the Operating Board set out to inform the future neighbors about the home to lessen the possibility of another battle over zoning. The administrator sent letters to everyone living near the proposed home, explaining the home's purpose, the way it would function, and the character of the women who would be living there. The administrator also went from door to door in the area to answer questions in person. However, opposition was started by one of the prospective neighbors. A petition was circulated against the new home. But at the zoning hearing, some of the people came forward and removed their names, saying that the petition organizer had misrepresented the facts. To strengthen their case, the organizers of the home had the city manager and chief of police of the Lupine House community provide letters of endorsement. The use permit required was passed easily, and the home opened in September 1973.

With confidence increased since the beginning of Lupine House, the ARC decided to buy, not rent the house. This was made possible by the $36,000 grant from the San Francisco Foundation. Ten thousand dollars of the grant was used for the down payment, with the balance going for administrator's salary for two years, furniture and home improvements. The new home is now operating successfully with six women.

Plans are also developing for a "sheltered apartment" near Lupine House, where several women would live on their own but with the support of Lupine House nearby. The Board is wholeheartedly in favor, and an apartment has been found, but the parents of one of the three women considered ready for such a move are opposed. They think their daughter is not ready for that degree of independence. It is likely that the apartment will be started before 1975.

Thus, the Lupine House Board is working toward graduated steps in residential settings--a structured home with 24-hour supervision, Lupine House, which has limited supervision, and sheltered apartments leading to fully independent living.

III. PROGRAM

The "motivating philosophy" of Lupine House is normalization. As stated in the policy manual, "this principle allows the mentally retarded to obtain a way of life as close to the normal as possible, making available to them the usual patterns and conditions of everyday life." Indeed the life in the home is very close to "normal" including the house itself, and the furnishings, the daily schedule, the arrangements for cooking and cleaning, and the relationships between the women who live in the home. The policy manual states that the goal of Lupine House is to provide young, adult, retarded women with a "stimulating environment in which to live and work together for greater personal independence and impoved self-image."

Independence

Independence as a goal was not originally a concept which all the founders of Lupine House shared. The idea was encouraged by the social worker who helped the parents in organizing the home and has since been adopted not only by the parents, but also by the residents. In fact independence has become a central theme of the home.

The most tangible efforts towards the goal of independence is the training in living skills which is an integral part of life at Lupine House. All of the housework and cooking is done by the residents. The housemother is a coach and advisor. Thus the women are responsible for keeping their own rooms clean, washing their own clothes, and shopping and cooking. Since most of the women are mildly retarded, they are able to do these tasks quite independently.

At times one of the women will forget to make her bed or her room will become progressively messier as she puts off cleaning it up. The housemother generally waits for a time before saying anything since developing self-discipline is one of the important steps towards independence. But if the condition persists, she may make a suggestion.

To provide experience in keeping their clothes clean, the house is equipped with a washer and dryer. Although it would be more convenient to wash all the sheets and towels at one time, these are done individually by each woman for the learning experience. All the women have become proficient in using the machines.

A written menu is a licensing requirement which has been turned into another learning experience for the women. Each week the housemother works with a team of two who will be doing the food buying for the week. They have to live within a set food budget, so they have become more alert to the prices of food and to what is in season. The housemother goes with them to the supermarket and assists the women in the food buying, although, as in other practices in the house, she trys to leave the decisions up to the women.

Since the women leave the house at different times in the morning, each woman makes her own breakfast and sack lunch. Dinner is the one meal when the entire household eats together. Supper is prepared by a team of two, and another team does the cleanup. The housemother provides only occasional help and instruction in cooking. The women have become skilled at preparing meals, teaching each other how to prepare different recipes.

One night a week is set aside for a cooperative effort at vacuuming, dusting and mopping. Although these jobs are supposed to be rotated, two of the women feel that they often end up doing more of the work than the others, while two others are overly fastidious about their jobs and have to be reminded to move on to the next chore. All in all, the women take great pride in the house and in keeping it neat and orderly. Peer pressure is as effective in getting the work done as is the guidance of the housemother.

Although all of the women had some experience in household work before coming to Lupine House, the deliberate program of teaching living skills has raised their abilities. Of even greater importance, increased ability has raised their confidence in their ability to take care of themselves. The theme of independence (and responsibility) is carried out in other details of the home. Each of the women has a key to the front door; the telephone is accessible to all with a pad for jotting down long distance calls; each may decorate her own room as she sees fit. When a doctor's visit is necessary, the housemother instructs on how to make an appointment, but she leaves it up to the resident to make the call. At first the women find these responsibilities hard, but after a few trys the tasks become easier.

Work and Job Training

All of the women at Lupine House have jobs or job training programs which they go to during the day. However, the work and the training are not very satisfactory to the women. The lack of meaningful work seems to be among their greatest problems.

Gladys and Donna commute to San Francisco each day catching a public bus which stops near the house. Gladys works at the U. S. Mint inspecting coins which she finds boring. "All I do is just sit all day and look at coins. I'd like to move around more and do different things,... I don't have any friends at work either, so sometimes I feel lonesome." However, the pay is good--$600 a month--so she can pay her own room and board and save some too. The financial independence is a good feeling for Gladys.

Gladys got her job through the assistance of her vocational rehabilitation counselor. Although she has training as a key punch operator, her speed is still too slow for competitive employment. She is hoping she can get a different job.

Donna got her job in a blueprint firm through a referral from a friend. At first she only trimmed blueprints, but now she has a job in which she can do a variety of tasks, and she finds her work interesting and enjoyable. Donna is able to pay part of her monthly fee from her salary and says, "I feel more mature now that I can pay my own room and board."

Three of the women work at a sheltered workshop which they find boring and repetitious. They very much resent the low wages. They wish there were a variety of jobs to choose from. Most of the time the workshop has only collating and assembly work which is monotonous for them. At times there are no jobs and they are obliged to create work for themselves which they find difficult to do.

After Penny had been at the workshop for over a year, she was tested by the local vocational rehabilitation office since she did not like the assembly type work. It was discovered that she has very little motor coordination, whereas the collating and assembly work she does all day requires just such ability. On the other hand, Penny does like housework, and efforts are being made by the administrator and vocational rehabilitation to find her a position as a domestic worker in a motel or nursing home where she could do work she liked and yet not be isolated.

Dawn has recently been trained at a Goodwill center to do cafeteria work. While looking for a job she is working part time in a convalescent home. Dawn has shown considerable initiative in following through on job leads the administrator and vocational rehabilitation have found for her, and in making appointments for herself.

Two of the women who are at the workshop also attend classes at a "chef's academy." They enjoy the classes and hope that they can learn enough to get jobs working in restaurants.

Perhaps eventually all the women will have full-time jobs which pay a living wage so that they can contribute substantially to their own support. However, as Gladys has discovered, even a well-paying job can be unpleasant and unrewarding if it is repetitious, dulling, and does not allow a person to use the skills that she has--even if the skills are limited.

Improved Self-image

The companion goal to independence is an improved self-image. Being more on their own at Lupine House, improving their living skills, and to the extent that the work situation improves, all contribute to the women's sense of being able to cope with the world and their images of themselves.

Gladys, for example, since coming to Lupine House, has improved her ability to cook. "At home I just helped Mother, and now I can do it myself." She has also learned how to manage money. With the housemother's assistance she opened a checking account and now pays her own bills.

Gladys, age 23, was among the first to move into Lupine House. She has an air of confidence and certainty about her. Although only mildly retarded she has a hereditary speech disability which causes her to speak slowly. She is somewhat shy with people she doesn't know and when she gets nervous it is more difficult for her to talk. She feels good about the way she dresses and about herself in general. She would like to get to know more people, particularly men, and is thinking about joining a bicycling club this summer to pursue one of her favorite activities. After almost four years at Lupine House, Gladys considers herself ready to move out to an apartment. Someday in the future, Gladys would like to buy a house large enough to rent rooms to other women.

One of the goals which Linda, her parents and the staff set for her at admission, was to become more involved with the others. Linda tends to be reclusive, spending long hours by herself in her room. She has made new friends--the women at the house, people at the sheltered workshop, and a boyfriend. Being at Lupine House in the company of others has been most helpful to her according to her parents.

Linda's brother has taught her Transcendental Meditation, and she practices it quite regularly. It does mean time alone in her room, but she feels it has a calming affect on her. Linda tends to be anxious and somewhat complusive. She is working hard on, as she puts it, "not pestering Paula so much." (She frequently consults her for advice.) A minor but nagging problem for Linda is what she calls "snitching food"--a habit which makes it hard to lose weight. One evening a week Linda, together with several other women from the house, takes a physical fitness course at the local junior college. She finds she enjoys the class as well as mixing with other people.

Linda's dreams for the future are to move into an apartment "in a pretty place with lots of trees," to get a good job, and to take a trip to England where her grandparents live.

Her boyfriend, Brent, is a mildly retarded young man who lives with his brother in an apartment nearby. She sees him once every two weeks and likes being with him, but she feels she "has to grow up some more" before thinking about marriage. "I don't think I want to get married, I want to stay happy like I am." Brent has been putting pressure on Linda to be sexually freer with him and this makes Linda upset. She feels he's too pushy about sex. Linda talked with the housemother about the situation and found her advice and guidance reassuring.

One of Linda's significant gains in self-image came about through a difficult problem she had with one of the earlier residents. Linda was frequently "put down" and snubbed by another woman who was a general behavior problem for everybody in the house. Linda, having spent all of her life with her family who were kind and supportive to her, was unprepared for this onslaught of abuse. She became more withdrawn and depressed, finally going back to her parents' home. Her parents found a

psychologist who counseled her to "stick up for Linda." The difficulty ended as Linda lost her fear of the other woman. In the process, Linda learned she could stick up for herself.

Donna's most significant change since coming to Lupine House is in her relationship with her parents. She says, "I like Lupine House much better than my home because here my mother is not on my back nagging me all the time." Relationships with her parents have improved now that she is away from home. She says, "I feel closer and happier with them than I used to." Although she only visits her family once or twice a month, when she does she enjoys the visits. She feels proud that she has made the move away from them because she wants to learn to live alone, particularly, as she puts it, "since they won't always be around."

Since coming to the house Donna has learned cooking and housework. The meals she has been helping prepare, "have been coming out beautifully." Her efforts at housework she calls "pretty good." However, Donna finds it a struggle to get her personal chores done. She now gets her washing done promptly, but she wants to be more disciplined about bathing and washing her hair. She is not certain whether she will ever solve the problem of getting up on time.

Donna saw the movie "True Grit" and was impressed with the heroine who was strong and self-confident. She dreams about being strong like her and not being "grouchy" when she is tired. She would like to move to an apartment, but it would have to be near Lupine House so that she would not be lonely. She would like a wider group of friends than her present group which includes her boyfriend, her mother's friends, and the women at Lupine House. She believes that living in an apartment would be, literally, more healthful for her, "I won't get so sick as now." A curious comment, revealing her intuitive understanding of the interdependence of her emotional and physical lives. One of Donna's long-term hopes is to take care of babies because she likes them so.

Like Donna and Linda, what has changed most for Kaye since coming to Lupine House is her ability to relate to others. Kaye who is 21 has been living at Lupine House for a year and a half. She is tense, energetic, talkative. Because of a hormonal disorder she is small and girlish in appearance. Often she is taken to be younger than she is.

Although Kaye sees her parents only every few months, she has developed a small group of friends who are important to her. Kaye feels that relationships with friends have improved because she doesn't talk as much as she used to. She sees a psychiatrist once a week, and until recently, took part in group therapy sessions which had to stop for lack of public funds. She misses the group and hopes it will start up again. The combination of therapy, improving her living skills, and being with the other women at Lupine House contributes to Kaye's improved self-image. She feels that she is honest and kind, sincere and helpful. She is working hard on "not talking so much," and on listening to others.

With the housemother's help Kaye is working hard on learning to handle money. More than once she has spent her pocket money on candy

and other frills only to find she has none left for carfare. For the time being the housemother keeps Kaye's money giving Kaye the amount she asks for each day. As she gets more experienced in handling money, she will be able to keep her own money. In the future Kaye sees herself moving to an apartment with a roommate. Eventually she would like to get married believing that "a man would keep me in my place."

Another resident, Penny, also is assertive and talks a great deal, although unlike Kaye, she is not as aware of the affect on others. Penny, who at 32 is the oldest woman at Lupine House, has had the most difficulty in adjusting to the home. When she lived with her mother she had much greater freedom and finds it difficult to cope with rules such as not being in the home alone (a state licensing requirement). Penny had been seeing a psychiatrist once a week for feelings of tension. However, the therapy was broken off by the therapist who felt she could not do anything more for Penny. Her tension often is unleashed against the other women in the home by being "bossy" or dominating the conversation.

Penny has been obsessed and upset by the Watergate hearings. She had been watching the television at every chance she got, compulsively memorizing the smallest details and loudly interrupting conversation to announce the latest news. This bothers the others and they tell her so. As a Republican who deeply believes in President Nixon, she is bewildered and upset that the allegations might be true.

Penny also has a comic side, teasing the others and making jokes. They have nicknamed her "Peppermint Penny" after the character in "Peanuts," and although her personality sometimes rubs the wrong way, the others in the house appear to have a genuine fondness for her.

In living closely with others, Penny is slowly learning that she must take the feelings of others into consideration. Prior to coming to Lupine House she had lived at home alone with her mother. Apparently many of her tensions and boisterous behavior stem from the protective relationship with her mother, which cut her off from wider social contacts.

Penny's great love is Wyoming. She has spent vacations with her family there and collected bulging scrapbooks of photographs and postcards. She can talk endlessly about the cities and mountain ranges and places she would like to go back to. Her dream is to marry a cowboy, move to a big ranch and raise horses and cattle. It is an odd dream, because she is not athletic or an outdoors person. No one seems to take her seriously about the dream. It is just one of Penny's things.

Dawn at 19 is the youngest woman at Lupine House and the opposite of Penny. She is shy and quiet often daydreaming about her boyfriend as she slowly twists her long blond hair around her finger. Before coming to Lupine House, Dawn lived at home but she says she did not

get along well with her mother. She enjoys the freedom of Lupine House and being away from the constraints of her home.

Since coming to the house she has learned to wash her clothes, clean house and handle money. She enjoys cooking, but would like to do it more so that she can get better at it.

Along with two others in the house Dawn takes a reading and mathematics class at the local junior college (these are classes for people who have been out of school for several years and are considering entering college or need their skills improved in order to get a job.)

Although Dawn has lived at Lupine House for only six months, she has fit in well. She has no big problems but would like to get over being shy. She is too young to strike out on her own yet. In the meantime, Lupine House provides a warm, supportive environment for her to mature and learn new skills.

Improved self-image is a very real goal for Lupine House, even if it may be hard to measure the gains toward the goal. It is evident from talking with the women, the housemother, administrator and parents that the style of the house which allows the women to maintain the home themselves has given the women a sense of being able to take care of themselves. True, they do need the housemother's support and guidance, particularly when they are faced with a new situation. However, they are given the opportunity to learn through doing, and the skills they develop appear to give the women a better appreciation of themselves.

Security

While independence and improved self-image are explicit goals, the goal of security is implicit. For the parents, security has several dimensions. First, they want their daughters to be safe in daily life, and this is provided by the housemother who is on hand whenever the women are in the house. Second, they would like the home to be financially secure so that the home is on-going even if they could no longer support their child or if they should die. Lupine House is approaching the point of financing based on state and Federal support payments and to some extent the wages of the women. However, continued state support is uncertain because there may be program cutbacks.

The other side of being secure is taking risks. It is through risk-taking that a person has new experiences and is able to grow. But risks at Lupine House are minimized in large part because of the pressures of the parents (or the concern by the staff of what the reaction of the parents might be). For example, the reluctance of parents to allow their daughter to live in a sheltered apartment. In another instance one of the girls went to the housemother to talk over a problem about her boyfriend who was urging her to have sexual relations. The housemother,

feeling that the woman was not ready for a sexual relationship told her that she would have to leave the house if a relationship started.

Finding the balance between security and risk-taking requires judgment and a constant reappraisal of the particular situation and the capability of the women. It is apparent that the women of Lupine House are willing to defer to the judgment of the housemother or their parents. Since it is easier and safer to avoid situations where there are risks, the choices are usually structured so that there are few risks.

Friendship

Another implicit goal for Lupine House is providing a warm, supportive atmosphere where the women can make friends. For most of the women loneliness and isolation were a real problem when they were living with their families. This was particularly true as they finished school and that major contact with the outside world ended.

All of the women in Lupine House commented on the importance of their relationships with the others in the house. Four of them have been together in the home since it started which was almost four years ago. Their relationships with each other as well as those with the housemothers have resulted in friendships that are among the closest they have.

IV. OBSERVATIONS

Lupine House is considered a "good" home by its residents, their parents, and professionals who know the home. What makes it a good home? What were the decisions and actions that made it a good home. Will it continue to be a place of excellence in the future? And for others interested in organizing their own home or who are presently involved in an ongoing home, are there lessons from the Lupine House experience that are applicable to other homes for retarded people? In this concluding section we have identified what appears to be the significant and exemplary features of the Lupine House experience.

Philosophy and Ideology

Not by coincidence are philosophy and ideology discussed first, for they are the underpinning of this home (and any other human service organization). To understand the philosophy and ideology of the home is to understand why many of the decisions are made, and how the style of the home is consequently shaped.

Normalization is the operating philosophy of Lupine House clearly stated in the Policy Manual. Wolfensberger offers as a definition: "Utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible."* For Lupine House, what this principle means is that the home, the daily schedule, and the lives of the women should be as similar as possible to that of other women of the same age and background. Normalization is not something which is discussed on a day to day basis. It is, in effect, a somewhat distant guideline. But from time to time it is used as a reminder when a new decision is at hand. For example, the question came up of photographs of the women to be included in this report. The administrator checked with a lawyer on the Advisory Committee for his opinion. He said the women were legal adults, and they had the prerogative to give permission.

In many ways Lupine House meets the standards of normalization.** The House in its location and decor are much like other homes in this residential suburb. The women's clothing, possessions, schedules and so forth are very much like any other group of young, single women who are roommates in a suburban community.

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* Wolfensberger, Wolf, The Principle of Normalization in Human Services, National Institute on Mental Retardation, Toronto, 1973, p. 28

** For a detailed analytic technique for evaluating human services based on the normalization principle, see Wolfensberger, Wolf and Glenn, Linda, PASS, Program Analysis of Service Systems, National Institute on Mental Retardation, Toronto, 1973.

In the crucial area of risk taking the program at Lupine House is cautious. Perske in a landmark article, "The Dignity of Risk" observes, "Where many of us worked overtime in past years to find clever ways of building the avoidance of risk into the lives of our clients, now we should work equally hard to help find the proper amount of normal risk for every person. We have learned: there can be such a thing as human dignity in risk and there can be a dehumanizing indignity in safety."* The operational difficulty is defining what is the "proper amount of normal risk." Certainly the state licensing regulation that a retarded person may not be alone in the home is not appropriate for Lupine House. However, in the rules and norms of the home there are areas which are open to question. In sexual relationships a fine line is attempted. Dating is encouraged, but when a boyfriend of one of the women made it known he was interested in sexual relations, the housemother, in order to protect the women, told her it was against the rules. The women are also not allowed to have men in their bedrooms. It may well be that the women are not yet ready for the normal risk taking in full heterosexual relationships. For most of us, sex, love and marriage are experiences with potential unhappiness. But they can also be experiences of great joy and fulfillment, and a person cannot know them unless he risks involvement and commitment.

The cautious approach in risk taking is mainly due to the influences of the parents. Although the parents are not involved in day-to-day matters and they are numerically a minority on the Operating Board, still their views and concerns have great weight. The parents are often more cautious than the staff and Operating Board.

Even though normalization is a somewhat distant guideline in the day-to-day affairs of Lupine House, it has influenced the character and life-style of the home. The ideology which has been hammered out by the parents and the Operating Board and codified in the Policy Manual is positive and oriented to the development of the women. The ideology, then, is one of the keys to the successful development and operation of the home.

Beyond Normalization: Independence

If normalization is a distant guideline, independent living is a more evident and operational goal. At the time Lupine House was organized, most of the parents had in mind that it would be a long-term residence for their daughters. While the parents were not opposed to their daughters living independently, it did not seem to them to be a possibility. However, the women have demonstrated that they are quite capable at handling most of the responsibilities of managing and running a home. As a result, the

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*"The Dignity of Risk" in The Principle of Normalization in Human Services, Wolf Wolfensberger, National Institute on Mental Retardation, Toronto, 1973, p. 20.

outlook of the parents has shifted. Independence in living is now seen as a major goal for the residents, with the home being a step towards independence. The women see this as a goal for themselves, although they very much want to live near Lupine House to be in touch with their friends.

To date, the goal of independence has not been fulfilled. Of the two women who have left, one was later admitted to an institution, and the other was married for less than a year and is now living with her parents.

The plan for satellite apartments is a logical step in the progression toward independent living. There are many problems to be worked out. For example, suppose a woman is unable to live more independently. Should a place be kept available at Lupine House for a period of time so that she could return? Does keeping a place open make it too easy to return. Is it too protective a strategy?

Setting

A basic reason why Lupine House is "good" is the quality of the home itself and its location. The home is pleasant and comfortable and the furnishings are of a quality comparable to other homes in this upper middle income suburb. There are no institutional features such as exit signs, special locks on the doors, or indestructable, impersonal furniture. Indeed the home has special features that make it particularly attractive: a sheltered patio area for lounging in the sun; a large dining room; and a family room with a view out to the trees.

Although the home has a pleasant sense of seclusion, it is conveniently located. Public transportation is within a short walking distance, and the town center is within walking distance. Although there is a house-owned van for trips together, the women are not dependent on the housemother for transportation.

There is a subjective, but revealing test for a home. Ask yourself, "Would I like to live here?" In the case of Lupine House, the answer would almost always be "yes."

Parent Involvement

A unique feature of Lupine House is the role of parents in organizing the home. Although they were assisted by a social worker and have picked up other supporters from the community, Lupine House exists because of the efforts of parents. In the beginning, the parents had little knowledge or guidance about organizing a group home. Fortunately they had considerable organizing and administrative skills from past experiences in business or from other community organizing experiences (the two key organizers had worked together to get a nursery school going).

Now that the home is organized, parent involvement has decreased. State funds now provide financial support where parents previously had to. The Operating Board has only three parents out of 15 positions. The administrator is a parent, however, and on important decisions she consults with parents or at least takes into account what their interests and opinions are.

Although parent involvement is not daily, the administrator of Lupine House makes sure that parents continue to maintain a sense of involvement and responsibility for their daughters. During the first year there was a problem. A woman was placed in Lupine House, and her parents went to Hawaii assuming the House, like an institution, would take care of their daughter and their involvement was not necessary. As a result, a rule was developed that a parent or guardian "must live close enough so that the resident may visit and/or receive visitors for at least the six-months probationary period."

Administration and Staffing

It is a truism in the operation of small group homes that the personality and style of the houseparent is a key determinant in the way the home operates. At Lupine House, while this is true, the role of the administrator is also highly significant. Though there has been some turnover in the housemother position, the overall quality of the home has remained consistent and the objectives have not basically shifted. The administrator has provided the necessary continuity in policy and style.

Each week the administrator and the housemother meet and review any problems that have come up. Considerable time is spent reviewing the approach the housemother should take for each woman. This method provides perspective and objectivity that is difficult when a person is involved in the day-to-day program.

There are other aspects of the administration which are worth noting: the development of the Policy Manual, the creation of the Operating Board and the Advisory Committee, and the relationship to the local ARC which provides continuity for the program.

Availability and Use of Community Resources

No matter how excellent the life within Lupine House, for the home to be successful there have to be available community programs and resources. Fortunately, there are a great number of good quality community resources. For example, there is public transportation, the local community college offers courses which the women can participate in, there are vocational

training programs and counselors to help the women find work, there are psychiatric counseling services, and recreation programs. Not all of them are perfect. Indeed the single most vexing area of the women's lives remains the world of work.

Also, their recreation and social life is limited. With friends limited to the other women in the house, a boyfriend, and few others, a social isolation remains a problem for most of the women.

Summary

Creating and maintaining a good home is an art, very much like cooking a gourmet meal. One can describe the ingredients and spell out the processes, but unless the chef can put it all together with a sense of caring and love, it won't be a masterpiece. Caring is the magic ingredient.

For Lupine House the sense of caring is indeed there. Beyond that essential ingredient, what seems to account for its being a "good home" is:

-- a philosophy based on the normalization principle with the specific goals of helping the women become independent and develop a better self-image.

-- a pleasant physical setting integrated into the community.

-- a high level of parent involvement balanced by professional and community representatives.

-- an efficient administrative structure that is able to provide both continuity and perspective, and

-- available community resources which provide the vital out-of-home life for the women.

C.

THE HEARTH

The first Vanier-inspired community home in the United States

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I. INTRODUCTION

Whether openly stated or implicit, the philosophy of a community residence is the underpinning of its approach, its program, its distinctive style and even its architecture. The Hearth, in Erie, Pennsylvania, is a home based on a philosophy of Christian community and a concept of retarded people which is distinctively different from almost all other community residences.*

The Hearth is the first community residence established in the United States which is part of a network of communities for the retarded called L'Arche (the ark). Founded in 1964 by Jean Vanier in a small village in France, L'Arche now has 16 other homes throughout France, two in India, one each in Denmark, England, Scotland and the Ivory Coast, and eight in Canada. A second home has started in Clinton, Iowa, and another is about to open in Mobile, Alabama.

What makes L'Arche different are first its Christian values. These values include simplicity and poverty (in the sense of detachment from cultural riches), the importance of caring and loving between people, and the acceptance of retarded people simply because they are fellow men and women. Secondly, members of L'Arche view handicapped people as capable of experiencing deep spirituality, in part because of their "suffering" and partly because their intellectual limitations allow them to be more ingenuous--to have less pretenses. A third distinctive characteristic is the elimination of professional (i.e., staff) and client or resident distinctions. At L'Arche communities the "assistants" as the staff are called, <u>live with</u> the handicapped rather than <u>working for</u> them.

In commenting on the L'Arche communities, Wolfensberger** believed that they are significant because they have, "a tremendous power to inspire the young and bring them into the field," and because the experience of relating to the retarded "spiritualizes and inspires people in other aspects of their lives, brings spiritual depth to their functioning, helps them be better citizens and human beings." In other words, by creating a sensitive and caring community, the L'Arche movement has revealed that the retarded have something of value for the non-retarded. So often society and those working with the retarded see themselves as giving to

*Camphill Villages started by Rudolph Steiner have some similarities. However, their concept of "sheltered villages" are different from L'Arche communities which turn outward to be a part of community life.

**Professor Wolf Wolfensberger has prepared a monograph on L'Arche, "A Selective Overview of the Work of Jean Vanier and the Movement of L'Arche," National Institute on Mental Retardation, Toronto, 1973.

the retarded without recognizing what they are or could receive from the retarded. This notion--that the retarded have something of value which can help us realize our humanity--may be the significant contribution of L'Arche.

This case study attempts to describe the philosophy of L'Arche and life as it is experienced at the Hearth. But, as one of the founders of the Hearth observed, "The realities of L'Arche are for me as deep as the mysteries of human existence..."

II. VANIER AND THE DEVELOPMENT OF L'ARCHE*

The founder and moving force in the L'Arche movement is Jean Vanier. Although Canadian, Vanier spent most of his childhood in France and England since his father was in the diplomatic corps. From the start Vanier was marked for success in the conventional manner. He was from a distinguished family (his father rose to become Governor-General of Canada). He studied at the Royal Naval College, Dartmouth and was commissioned in 1945. But in 1950 Vanier resigned his commission believing that military efficiency and technology were not the way to the human brotherhood and peace the world needed.

Vanier then began a long period of study, contemplation and searching. He went to Paris to study at the Institut Catholique, where he joined Eau Vive, a student commune, directed by Pere Thomas Phillipe. Pere Thomas and the experience of Eau Vive had a strong influence on Vanier. He lived there for the next six years studying for the priesthood. But then he withdrew before the final year. He spent several years alone--living and studying in a monastery, by himself, in a farmhouse, and in Rome with Pere Thomas. In 1962 he received his doctorate in philosophy and joined the faculty of St. Michael's College at the University of Toronto.

During these years he came to the conclusion that his calling was to form a community together with the poor and rejected of society and to live a life of simplicity, caring and spirituality.

In the meantime Pere Thomas had become chaplain of Val Fleuri, a residence and workshop for 20 retarded men in the small village of Trosly some 41 miles north of Paris. Pere Thomas encouraged Vanier to come there and start a residence for retarded people. In 1964 Vanier bought an old house in Trosly and moved in with two retarded men, Raphael and Phillipe. Without a particular plan or backing, he made the commitment to live with these men for the rest of his life or theirs. The search for direction was over.

Within three months, Vanier's responsibilities were expanded when he was asked to take over the direction of Val Fleuri. From only two people in 1964, L'Arche in Trosly has grown to a complement in 1974 of 150 handicapped people and 150 assistants in 13 houses scattered throughout the village of Trosly.

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*This section is derived from the insightful book by Bill Clarke, "Enough Room for Joy: Jean Vanier's L'Arche: A Message for Our time," McClelland and Stewart, Toronto, 1974.

Concepts and Practice

Vanier's original notion was to establish "a home of mercy where the rejects of society could find refuge and where they would be welcomed with kindness and compassion." In other words, the staff would provide, the handicapped would receive. But the experience of living with retarded men soon convinced him that they had both the ability and the need to give to others. Others who came to L'Arche to work quickly recognized how much they themselves received from living with the retarded men. The "gifts" were simple lessons of love, compassion, simplicity and joy. In a sense people found dimension and meaning in their own life by experiencing life with the "boys" as they are affectionately called in France. Many assistants comment how much they appreciate the genuineness of the relationships with the residents; relationships free of pretense, status, or appearances. One of Vanier's central messages, therefore, is that no matter how handicapped a person may be, he has great dignity and the capacity to enrich others. Clarke, who spent three years at L'Arche, summarizes the qualities of the residents which the L'Arche atmosphere draws out:

> ...simplicity of spirit; affection and freedom to genuinely manifest this affection; candidness; openness to life, to people, to God; capacity to make people feel welcome; tendency to be concerned only with the essentials in life and in people; joy and an eagerness to give joy to others; generosity; capacity to live fully the present moment; sense of wonder; sensitivity; unquestioning faith.

As Vanier sees it, retarded people are "wounded" people as we all are wounded in some way.

> Since their infancy almost all the handicapped have been wounded not only organically but by so many looks of pity, disdain and indifference that have made them feel worthless, and inferior and have destroyed any confidence they may have had in themselves.

There is also the recurring reminder that they are dependent on others and some may never be able to be independent. What handicapped people need, therefore, is the love and acceptance of people.

Aside from the obvious work roles which assistants at L'Arche have, their main function is to live with and "be present" for the handicapped. To do this requires considerable personal commitment and it is not easy. Clarke, describes what being present means:

> ...this is precisely the essential work of the assistants, to be present to assume or absorb some of the anguish of those who are suffering from wounded intellects and nervous systems, and from the life of rejection which these wounds have incited. This aspect of the work of the assistants of its very nature entails considerable suffering and unites

them to the handicapped in a very unique way, that is by compassion. This word compassion here must be taken in its literal sense, to suffer with. It is not a question of pity, but of entering into the other, of trying to resonate with him. (pg. 97)

Speaking of the assistants, Vanier sees them as "people who accept him and say 'I accept to come and live with you, Raphael, and to be with you because I love you and because we can have a really great time together, and because we can have a community together.'" At the same time L'Arche does not want assistants who are there to get a good feeling because they have worked with the handicapped. They don't want "do gooders".

The Charter of the Federation of L'Arche, which was organized formally in 1972, sets forth their objectives as follows:

> The first aim of L'Arche is to create communities inspired by the Beatitudes and the spirit of the Gospel. These communities seek to be communities of peace where handicapped and assistants live, work, pray together, sharing their sufferings and their joys like brothers. They know that they are all handicapped: for some the handicap is more external and for others it is more internal (selfishness, pride and so forth).
>
> The communities, far from withdrawing from society, would like to act as leaven in the dough, contributing in their own way to the transformation of that society. (Transformation of the characteristics of individualism, pleasure seeking, acquisition of riches and power, the priority given to intelligence and technique.) They wish to help society find hope and thus come to a system of values closer to those of the Gospel.

Enough Room for Joy

One of the most noticeable differences in L'Arche communities which visitors report is the sense of joy which the people have there. Wolfensberger, in his study of L'Arche communities comments:

> I can scarcely begin to define what I mean by joy in the lives of the retarded because one has to experience this phenomenon to understand it. But I believe that such joy is derived from a combination of sources and activities: the spiritual life...; a feeling of being valued and esteemed by the others in one's life; the love experienced from several of those in one's social environment; and

occasions at which one meets in a relaxed and free social atmosphere devoid of certain of the tensions and drives so common in the mainstream of our society.

Celebration is a key part of life at L'Arche. At Trosly there is the daily mass which, although voluntary, draws a large number of the retarded and assistants. Meals, particularly the evening meal, is a time of celebration. It starts and ends with prayers which seem to draw the community together and is marked with conviviality often singing and sharing of news. Christmas, Easter, birthdays, departures, arrivals, visits, Sundays, vacations and weekends are all taken as special occasions for celebration.

Vanier on celebrations:

> The celebration is that which relaxes the person in the depths of his sensibilities, that which opens him to others and to the universe. It softens hardness of heart and spirit. It creats unity between persons. It is the sign of the happiness of the eternal celebration.
>
> These celebrations, just as the community spirit, imply a whole world of symbols, a "liturgy" of life. It is up to the whole of the community to live these symbols, and to the home to develop their own style of life--each one a little different from the others--and to create a feeling of belonging to the community. Thus, it is good that each home develop its "liturgy of meals, prayer in common, get-togethers, etc.

The greatest celebrations of L'Arche are the annual pilgrimages which have been carried out since the beginning of L'Arche. Twice there have been trips to Rome and in other years the pilgrimages have been to Lourdes, Fatima, La Salette, and most recently to Canterbury. In addition to the adventure of travel the pilgrimages are convocations of the different L'Arche communities. There is great enthusiasm at seeing members of other communities and sharing experiences with them. The pilgrimages become both a religious experience and a holiday.

Community

As must be clear, the sense of community is a fundamental objective of L'Arche. But these communities are not introverted or exclusive. Indeed the opposite is the case. The L'Arche communities strive to be welcoming to all people. Thus, members of other L'Arche communities are encouraged to visit and their coming is cause for celebration. Visitors are also welcomed (although the number of visitors interested in Vanier's work poses particular problems for L'Arche at Trosly) as are those in the village and neighborhoods where L'Arche communities exist.

There are, the, several dimensions of community: first, among the members of the home itself; secondly the community of relationships to the surrounding neighborhood or town, and finally the community of L'Arche establishments. With other L'Arche homes there is a great amount of visiting, correspondence and keeping in touch.

III. DEVELOPMENT OF THE HEARTH

The origin of the Hearth in Erie, Pennsylvania, the first L'Arche home in the United States, dates back to 1971 when Father George Strohmeyer and Sister Barbara Karsznia, instructors at Gannon College in Erie, attended a retreat led by Jean Vanier. They came away from the retreat greatly moved and called forth by Vanier's message. In January 1972, they visited L'Arche at Trosly for four weeks where they lived and worked in the community and got a sense of how it worked.

It became clear to them that "unless a mentally handicapped person has another person who becomes his brother or sister, to live next to him, in order to share their total lives--their possessions, their home --the handicapped can never attain liberty, or the autonomy that is rightfully theirs."

Upon their return, Father George and Sister Barbara met with one of their former students, Cheryl Ott and her parents. This core group made a commitment among themselves to open a L'Arche home. During the year the group spent Sunday evenings with retarded people who lived at the Dr. Gertrude Barber Center for the Retarded, a residential center and "Base Service Unit" for retarded in Erie County. They would pray, sing and socialize with the residents at the Center. From this experience they gained a greater knowledge of how to be with retarded people. They also met on Friday nights with a local organization of handicapped persons sponsored by United Cerebral Palsy.

By April of 1972 they had successfully made contact with the rehabilitation counselor at Polk School, a nearby state institution for the mentally retarded. The counselor obtained permission to release two men and two women to the group once they had a home established.

The group's effort to find a suitable house was finally realized by the fall. The Ott's agreed to put up the down payment necessary for the $10,000 home. Father George and Sister Barbara pledged their salaries from teaching to support the home. By November four residents were released from Polk and moved to the home which would be called The Hearth, a center of friendship, radiating warmth and love. Sister Barbara and Cheryl Ott lived in the home as assistants, and Father George, who lived at a rectory across town, participated in the activities of the home on a daily basis while still teaching at Gannon College.

The Hearth was now launched, but there remained much work to assure its continuation. At Vanier's urging, a board of directors was formed "to protect" the fledgling home. The board currently is composed of eight people who all endorse and support the L'Arche philosophy. They include: the Chairman of the Department of Education at Gannon College,

the administrator of a local convent, a building and construction contractor, the Director of Housing and Neighborhood Development Corporation (who has been helpful in financial and real estate matters), a business education teacher, the wife of a local judge, a representative of the County Mental Health-Mental Retardation Office, and finally the Director of Daybreak, a L'Arche community in Toronto.

In the interest of getting a home started quickly, the Hearth was established without involvement of state or local mental retardation agencies. Pennsylvania has an active state program for developing and funding community residences called the Community Living Arrangements program. It works in conjunction with the county Base Service Unit which provides diagnosis, counseling, referral and back-up services.

When the Base Service Unit became aware that the Hearth was operating, it asked the state to investigate the Hearth to make sure it was providing quality residential care. The state then sent two assistants to the Hearth to check it out. They arrived when everyone was sitting in the back yard celebrating one of the resident's birthdays. They were obviously convinced by the spirit and ambience of the home, for, as an observer commented, "They asked us questions about the home, but they didn't even ask all the questions they were supposed to." A few weeks later, the director of community residences came to the Hearth and okayed the home providing some state requirements were met: installation of smoke detectors, fire escapes and rewiring. Indeed, the Hearth was invited to submit a proposal to receive state funding, and the state has worked with them in providing funds for house renovations.

The Home

The home is a two-story, single-family, frame house which formerly was much like other homes in the aging neighborhood. However, the neighborhood is beginning to come back as the result of a city housing rehabilitation program. Using renovation grants from the state, the Hearth is being improved and now has a value of $37,000. New aluminum siding and shutters have been added to spruce up the exterior.

Inside there is new wall to wall carpeting, freshly painted walls, and new drapes and covers on the furniture. There is a large living room with a fire place, a smaller adjoining room that once was the parlor and now houses the television and record player, a dining room, with a long table where everyone eats together, and a brightly painted kitchen that is often the center of activity as meals are prepared or dishes washed. The back porch has been winterized and has laundry facilities and workbenches for craft projects. Upstairs are four bedrooms; one of which is used as a prayer or quiet room.

The neighborhood is less than a mile from the downtown of Erie. It is a neighborhood of transients--students and poor people, people living alone and rooming houses. Some of the buildings stand vacant, waiting to be renovated by a city housing rehabilitation program. Change is occurring, however. Already six homes have been renovated and more are planned.

For years the neighborhood had been declining. Then in 1968 the City Council put a zoning "freeze" on the neighborhood limiting the number of unrelated individuals who could live in a home to five. The Hearth is presently trying to change their zoning designation so that up to eight people can live in the home which will be a more suitable number both economically and to have a sense of community.

The location has many advantages. Community facilities are within walking distance, there was no opposition to locating the home there, and the house was inexpensive. Nearby are the library, museum, bus lines, the post office, department stores, doctors and dentists and hospitals.

The Hearth also rents a home across town next to the rectory where Father George lives. It is a home used for extra volunteer assistants, visitors, guests, and short-term residents.

The Program

In keeping with the L'Arche philosophy of living with the handicapped, the "staff" at the Hearth consists of Sister Barbara and an assistant who live at the Hearth, plus Father George who spends a great deal of time there. The second home is staffed by a former school teacher from Chicago. Since this is their life, they do not work a set number of hours. However, there is a balance of work and rest maintained.

In addition, there are volunteers who come to live in the Hearth community for varying lengths of time--from a few months up to a year. One young woman came in the winter and left the following fall to live and work at L'Arche in France. A man came in January and left in May after having planted a large garden in the back yard; in the summer four volunteers came including a Jesuit seminarian.

The volunteers join in the life of the home, experiencing community, contributing as their interests and talents indicate, and learning about themselves. Thus, others come to learn the message and style of the Hearth, and some may go on to found similar communities.

Every morning at 7:00 Sister Barbara, Father George and the assistants meet for prayer. Although residents are invited to come, usually there is only the staff. Breakfast, and all other meals are prepared by the assistants and the residents together, usually with the assistant doing the organizing.

During the day residents either go to jobs which have been arranged for them or to training classes. Competitive employment is preferred because the pay is higher than at sheltered workshops and there is a greater chance of a person being able to eventually be independent if they want to. One woman works as a nurses aid at a geratric hospital; another is a housekeeper for a retired priest who worked at Polk State School for 15 years; another man who now lives on his own has two jobs --one as a janitor at a bank, another in a foundry.

The evening meal, like at L'Arche, is an important celebration of community. Father George usually says the opening grace in which he will mention particular events of the day which they have to be thankful for. The food is simple, and the conversation is warm and playful. One evening it is mentioned that there are bags of walnuts in the basement. Father George reminisces about his delight with chopped walnut pancakes. Someone remembers John worked as a cook in a pancake restaurant. He is cajoled into making walnut pancakes for breakfast and everyone is pleased, particularly John because his skills are being appreciated and he can do something for the others.

Although the Hearth is a little less than two years old, there are already a circle of friends in the community who drop in from time to time. Being in community with people outside the home is an important part of the L'Arche concept. For the handicapped it provides a wider reference group and a sense of belonging. One such friend of the home is Andre, a young man in his mid-twenties who was a former student of Father George. Andre has been involved in many of the passions of the youth generation of the late sixties: radical politics, Eastern religions and more recently Transcendental Meditation. He frequently visits the house "because people are open and natural here." His four year old son, Jeremy, is a fast friend of several of the residents. He gave the house a hamster and comes to check on his rodent friend and pass the time with the house members.

Another close friend of the Hearth is an elderly woman who runs the House of Prayer in her small house a few blocks away where people may come to pray and talk with her. She knows the members of the Hearth and greets them warmly when they come to visit her. Across the street from the House of Prayer a group of young men are living together communally with a priest and they are also friends of the Hearth.

As at L'Arche, celebration is an important part of life at the Hearth. Not only are celebrations a way of building and sustaining a sense of community, they are also vitalizing and restorative for both the handicapped and assistants. Generally on Friday evenings there is a celebration with songs, stories, talk, discussion and tea or punch. Generally there are as many people from the community as there are residents. At one such celebration there was a discussion about the coming pilgrimage to Canterbury at Easter time. All the L'Arche homes will be sending people to the pilgrimage. It is described as a time of great friendship and spiritual uplifting. Several of the residents are scheduled to go and for most of them it will be the first long trip they have ever taken.

On some special Sundays Father George holds a worship service that is marked by its informality as much as its ecumenicalism. In December 1973 the Hearth began inviting people with cerebral palsy to their Sunday services since they usually could not attend regular church services (or often would not attend because they either were not made welcome or feared rejection). The "congregation" was made up of six people in wheelchairs, several of their parents, members of Hearth and several friends from the community. As with other Hearth celebrations there is singing and talking--the spirit is mellow and joyful. Some of the retarded people are quiet or even closed up. It may take months or even years for them to open up.

The "program" at the Hearth is really not a program at all. What happens occurs out of the dynamic of a group of people who have agreed to live together and who wish to be kind, patient and caring and to learn what responsibility to each other means. An example of how both self-esteem and horizons are changed by the Hearth occurred when Floyd came to visit. Floyd lived at the Polk School and was at the Hearth on a trial basis to see if he would like to come to live there. One of the assistants had been invited to visit her aging grandmother in Toronto. Father George asked Floyd if he wanted to go to Toronto. He could stay at Daybreak, the sister L'Arche community, and meet the people there and return a day later. The trip would involve a flight in an airplane, a totally new experience for Floyd. At first he could not believe the invitation was real, but when he was sure, he quickly accepted. He obviously was pleased to have the new adventure, and also to realize that he was important as a person to be asked to go. Although the Hearth budget is small, they do use their money for visiting and telephoning each other to keep the sense of community between the centers alive. As a Hearth proposal to the state phrased it:

> Socialization is not taught.... It is brought about by the very life-style of the home: the handicapped and the non-handicapped intermingling their total lives, the visitors who come to be present to other people and who wish themselves to be nourished by a group of friends who have committed themselves to each other, by the visits made to other homes and groups for the exchange of friendship and leisure as well as work time.

Effect on the Residents

The Hearth has been designated by the state as a "training hostel" with the intention that it be a transitional residence from institutional life to independent living. The Hearth's concept is that the residents are part of the Hearth community (as long as they wish to be part of it), so that whether a person is living in the home or in an apartment in Erie, he is still part of the family.

In the short space of a year and a half, three residents who lived for many years in the Polk School are living on their own. One is a man

in his early forties who had lived at Polk since he was 12. At first he was terrified at being in the community. A trip to the grocery store was an unknown and therefore difficult task. Yet he had the ability to learn quickly. Once shown how to do it, he caught on.

After several months he decided to move out of the Hearth to the "Y". Later he found a small apartment. He likes to tell the story of the first television show he saw at the institution. It featured a family sitting together in a living room. "Now can you imagine, here I am sitting in my own living room like that and watching TV."

Another woman lived at Polk for 29 years. After a little over a year at the Hearth, she lives in and helps run a home which offers young women in trouble overnight lodging. She also works full-time at a convalescent center. Two or three times a week she has dinner with her friends at the Hearth as well as inviting them to pot-luck suppers at her new home.

Another woman came to the Hearth at age 26 after 15 years at Polk. Her self-esteem, ability to care for herself and social development increased dramatically when she came to the Hearth. A job was found for her as a nurse's aide at a home for the aged, and it is a source of deep satisfaction and fulfillment to her. She now lives near the Hearth in her own apartment with her own possessions (and telephone!) She frequently visits the Hearth on weekends.

The organizers of the Hearth realize that it is not "the answer" for everyone. One woman had difficult emotional problems and left the home. In another case a young man lived at the home for six months and then ran away to continue his search for his family that cannot be found. He had been unable to go on the Cantebury Pilgrimage because there is no available record of his birth, and arrangements could not be made in time to get him a passport. As Sister Barbara admits, "Although some persons blossom in this type of situation, not every handicapped person will be able to adjust to a small, family type home after spending so many years in an institution."

Costs

The Hearth qualifies as a Minimal Supervision Training Hostel by the State of Pennsylvania.* To get started, Sister Barbara and Father

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*Pennsylvania has a large program for creating community residences for the retarded known as the Community Living Arrangements program. Funds are provided by the state for group homes of from six to nine people. To provide a continuum of services, nine types of living arrangements have been defined for state funding: (1) Life Support (medical), (2) Infant Nursery (child development), (3) Child Development, (4) Habit

George worked without pay and the house was purchased and operated on donations. However, because the state would fund such homes, an application was submitted so that once approved the state would finance the home.

The state provided $27,500 for renovating the home and bringing it into compliance with local code requirements. The 1974-1975 budget is $29,749. If requested zoning regulation changes are approved and there is a full complement of eight residents, the annual cost per handicapped person would be $3,719.

Table 1

The Hearth 1974-1975 Budget

Housing		
Rent	$1,344	
Maintenance and utilities	3,052	
Phone and supplies	1,414	
Equipment	1,800	
Loan repayments	7,012	
		$14,622
Food		$ 3,672
Salaries		
Full time	$6,300	
Part time	3,150	
Social Security	775	
		$10,225
Miscellaneous (licenses, accounting, etc.)		350
Transporatation		880
Total		$29,749

Shaping (psychology)--Specialized Youth Development, (5) Behavior Habilitation (psychology--corrective habilitational), (6) Training Hostel I--Young Adult Development (habilitation), (7) Training Hostel II--Sheltered Living--(social work or habilitation), (8) Training Hostel III--Minimal Supervision (social work or habilitation), (9) Crisis Assistance (social work and/or child development).

IV. OBSERVATIONS

The L'Arche movement and the Hearth, its first home in the United States, represent a different approach to providing community residences for the retarded than is generally found. What is the significance of their approach? Does it represent a model which others might follow?

Something of Value

The L'Arche conception of retarded people as having value--both intrinsically because they are human beings, and because they seem to have a way of being open, direct and loving--is of major significance in the way the L'Arche communities operate. Because the communities are infused with this ideology, these qualities of the retarded seem to emerge, often having been hidden or dormant for years.

One of the fundamentals of psychology which spans many different approaches is the idea that individuals need to have a sense of self-worth; that they are "okay." As Vanier has sensitively observed, the retarded are too often rejected, pitied, or in one way or another given the message that they are not okay. The social environment created and sustained at L'Arche communities is the positive, validating message "you are a person of worth, and significance. You have something of value."

Instead of judging retarded people from the conventional cultural values of productivity, intellectual ability, power, or physical appearance, the L'Arche values are those of love, compassion, openness, simplicity. Indeed L'Arche is not normalizing in the sense that they intend to prepare people for mainstream society. Vanier believes that mainstream society's value structure and direction needs changing and he hopes that by creating Christian communities, societal change might be effected.

Vanier believes that the ability to have such a positive relationship with handicapped people is influenced by God. In the April 1973 Letters of L'Arche he wrote:

> A new energy is needed to enter into the world of community: to meet persons as persons. We need a capacity to love which is not of this world and which enables us to detect in the heart of another the qualities and potential which are often hidden beneath a forbidding exterior. Yes, it really needs the patience which comes from the Spirit of God to welcome each man as he is, without fear, and with hope.
>
> If some day the L'Arche communities were to shut themselves off from this divine influence, from this deepening of a universal love, they would quickly become institutions where

a hierarchical system based on professional competence reigned. The weaker, wounded members would be cared for in "a home" but not in "their own home."

Equal Relationship

One of the clearest manifestations of this view is the relationship of the staff to the residents. As described earlier, the assistants live with the residents as equals. Not all the differences have been made equal yet. At the Hearth, for example, the major decisions about spending money, admitting residents and the direction of the home are made by the staff. But there is a commitment of the staff to live their lives with the residents as equals. Father George takes his turn in washing the dishes along with everyone else.

Such a commitment is not for everyone. Being with the residents all the time can also be draining. In France L'Arche has arrangements with a monastery in Paris where assistants may spend time by themselves to find strength.

Community

One of the concerns that many parents have for their retarded sons and daughters is that a life in the community may prove to be a lonely life. Without the normal attributes which attract others, and often with impaired social skills, the retarded may end up living lonely, isolated lives, their only companion the television set. Indeed in an age of individualism, sociologist Robert Nisbet sees the need for community as the outstanding social problem of the twentieth century.

Unlike all the other homes in this study, L'Arche purposefully builds community through the concern and attention for each individual in the home, the celebrations, and the family-like atmosphere of common meals. Even after people leave the home to live independently, they are considered part of the family and are welcome to join in its activities whenever they wish to.

Rather than creating dependency, the sense of community seems to give residents a sense that they have a permanent base or attachment so that they can experiment with living on their own. The community which the Hearth is building turns outward to the general community and is open and accepting of visitors and new members. Thus, it is not an isolated, sheltered community, but an open community of people. It includes not only the residents who live at the Hearth but also the circle of friends in the neighborhood, the volunteers who come for a period of time and depart, the board of directors and the people the Hearth outreaches to.

Conclusions

The L'Arche model of community for the retarded represents a type of relationship that is new. In the coming years there will undoubtedly be more L'Arche homes in the United States, although their numbers will always remain a small part of the total number of community residences. However, their influence in terms of style may have an effect far beyond their numbers.

There are some cautions which need to be noted about L'Arche. One is that people may be attracted to the movement or to working with the retarded for their own benefit, and retarded people, in one way or another, will end up being used. Those in L'Arche are quite aware of this problem. In a Hearth description of the program the point is made that, "Because the desire to serve handicapped persons can be a hidden desire to serve one's own needs, it is important that those who come to serve be evaluated and assisted constantly toward a more authentic motivation and expression of service." However, mutual growth and support is a part of the Hearth style since, as Vanier is quick to remind, we are all wounded in one way or another.

Another question is whether the L'Arche movement can continue in the same spirit and with the same energy without Vanier. He now functions as a charismatic leader and much of his time is taken up in visits, speeches and motivating members of the community.

The L'Arche movement is still young. Begun in 1964, it is only ten years old. The Hearth is a little less than two years old. However, in the relatively short period of its existence, L'Arche and the Hearth have made an impact on those who have experienced them as well as on the handicapped people who live in the communities. They are revealing a whole new way of relating to the handicapped.

D.

CHEYENNE VILLAGE

A program with graduated steps leading
to independent living in the community

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I. INTRODUCTION

Cheyenne Village's program is interesting because it offers retarded adults a guided pathway to independent living. The path toward independence begins at McLaughlin Family Lodge, a twenty-seven unit resort motel near Colorado Springs in which seven of the units are used by retarded residents. The highly structured program at the Lodge uses the motel work as a means of training in job responsibility.

When a resident has shown sufficient ability to work at a job in the community and to take responsibility for his own life, he moves to the staffed Training Apartments in Colorado Springs. Training in community living continues until the resident is ready to move to the next step--Counseling Apartments--where he or she lives on his own in a normal apartment. Staff visits in the evening to work out problems as they arise provide enough support to keep the residents from regressing. In the final step, independent living, counselors no longer visit residents. However, commitment to the residents' welfare is long term. A former resident may receive assistance to remain independent whenever he needs and asks for it.

In order to live in the community, a person must be able to support himself. A theme of the program is being able to work in competitive employment. Extensive training in job habits and attitudes toward work is followed through with a program to find jobs, place residents and continuous follow-up to assure that residents are able to keep their jobs.

A cornerstone of the program is a "reality approach" whereby residents are held fully responsible for their actions just as normal people are. Staff work constantly with residents to overcome dependency and irresponsible patterns of behavior fostered by protective parents and institutions. Residents are required to take responsibility by experiencing the consequences of their actions. This non-psychiatric approach to changing behavior appears to work and is a recurring theme in the program.

For those who have the motivation and potential to live independently in the community, Cheyenne Village provides an effective program of training, progressive steps, and long-term assistance that makes such a goal possible.

II. THE DEVELOPMENT OF CHEYENNE VILLAGE

Origins of the Cheyenne Foundation

The El Paso County Association for Retarded Children was formed in the early 1950's and in ten years developed into a strong organization with an endowment of over $500,000 and a board of influential Colorado Springs citizens. One of these was Mrs. Peggy Marshall, mother of a retarded daughter, who became the driving force behind the development of Cheyenne Village.

Beginning in 1965 Mrs. Marshall and other members of the ARC studied the problem of providing a residence where retarded and seriously handicapped young adults could learn to live independently. At the time, the philosophy of "obtaining rather than providing" was being developed at the national level, and the local ARC felt it would be inappropriate to get into the residential care business. Therefore, in 1967 a group from the local ARC formed the Cheyenne Foundation, a private, non-profit corporation, to develop a residential training center for young adults who had reached the end of their formal schooling.

For three years the group worked diligently: visiting homes around the country, commissioning cost studies by outside experts, searching for suitable facilities in the Colorado Springs area and raising funds from the ARC, a local foundation, and private contributors. The program which the board had in mind was a residential center for up to sixty people who would be employed in sheltered workshops or competitive industries during the day. A former girls school was considered as a possible facility but it was in an exclusive residential area and there would be a zoning fight which the Foundation felt it would not win. The plan was dropped.

A young executive director was hired, but he lacked experience in organizing residential facilities and consequently resigned within nine months. In spite of these setbacks, Mrs. Marshall and the members of the Foundation board kept their hopes alive and continued to search for a likely place.

Matters began to change when in September 1970 the board hired Alfred Bickford, previously the Chief of Educational Services for Children at the New Hampshire Hospital. Bickford, age 36, had recently come to Colorado from New Hampshire, fed up with administrative constraints there. Now he was offered the opportunity to organize a new program with the strong backing of a group of influential citizens.

McLaughlin Family Lodge Purchased

Bickford, together with a realtor from the board, searched the Colorado Springs area for a motel which could be converted into a residential center. They came upon the McLaughlin Family Lodge in nearby Manitou Springs, a motel with twenty-seven units, nine acres of land, attractive grounds with a mountain stream and a swimming pool. Although the motel was not up for sale, an offer was made, and the owner agreed to sell for $366,500.

Through the board, an anonymous donor was found who pledged $100,000 over a three-year period. The ARC donated $25,000 and other smalled donations were obtained to meet the $73,000 down payment for the lodge. Several members of the board agreed to sign the mortgage, and the long-dreamed of program was born.

Two cottages were remodeled to meet state health department requirements, and Cheyenne Village opened on April 1, 1971, six months after the new director was hired. Initially there were twelve residents selected from state institutions, local families and from the welfare department caseload. Bickford and his wife, a former dean of a women's college and a college graduate in physical education, were the staff. To meet the initial payroll, a bank loan of $6,000 was needed. But once the program got operating, it continued to expand and soon became financially solvent.

Since the Village residents were using only two of the twenty-seven motel units and summer reservations were coming in, the board decided to continue to operate the motel using it as a "sheltered workshop" where residents could be taught job skills in a real, business setting. Residents are trained to make beds, clean cottages, care for lawns, operate the laundry, and do maintenance. Working at the motel proved to be an effective means of training in work skills, attitudes and normalized behavior. By being in daily contact with tourist families, the residents adopt normal mannerisms and learn to become more socially acceptable.

Some of the board members had originally intended that the motel operation be phased out and the Village become totally a residential facility. However, the first year's experience made it clear that operating the motel was a vital part of the program of the center. On the recommendation of the director, it was decided to keep the motel operation as a vital part of the vocational training program.

By the fall of 1971, Cheyenne Village was well established. Another eight residents were admitted raising the total to twenty. Two more cottages were renovated to provide semi-independent living for residents working in the community.

Residences in the Community

Another shift in approach from the early concept involved the motel as the first of several steps leading to independent living. Originally the residential center was to be a more or less permanent residence for the handicapped. The new director, however, had in mind a training program for independent living. Cheyenne Village would be only the first step on the way to independence with intensive training for work, leisure time and living. As residents proved themselves at Cheyenne Village, they would move to counseling apartments in Colorado Springs. To assist them, staff members would visit regularly. The resources of the Village, including vocational counselors would be available to help an individual if he lost a job, got sick, wanted help in buying a car or similar such circumstances.

It was found that many residents needed a more structured experience before moving from Cheyenne Village directly to the counseling apartments. In November 1973 training apartments were started. Instead of only visiting, counselors are on duty at the apartments during the late afternoon and evening hours providing assistance in meal planning, buying food, maintenance and all the other day to day problems of living in the community.

In 1974 a community home was opened. This is a group home in a duplex in a pleasant neighborhood of Colorado Springs. The group home is a semi-permanent home for people who are not likely to be able to live on their own in an apartment and yet are not benefiting from the training program at the Village. Supervision is more intense.

By July 1974 the program had grown to 73 residents: 30 at Cheyenne Village, 16 in the training apartments, 8 in the community home, 14 in counseling apartments, and 5 in independent living. Staff had increased to 46, and a 1975 budget of $594,000.

III. PROGRAM

Philosophy: Normalization

The program philosophy of Cheyenne Village is a mixture of "normalization" and its own style of reality therapy. According to the staff policy manual, "each handicapped person who enters the program should have a chance to live his life as nearly like that of a normal person as possible." What this means in practice is that the goal for each person is independent living or as close to independent living as the person is able to manage.

Each of the steps towards independence is increasingly more "normalized". For example, leisure activities at Cheyenne Village are generally done as a group which is considered not normalizing. However, when residents move to the training and counseling apartments, they are encouraged to find recreation in normal community programs such as the "Y" or going to the library on their own.

In many small ways the normalization theme is stressed. Staff and residents alike address each other by their first names. Staff refer to Cheyenne Villagers as residents rather than "kids" or "boys and girls". Residents are allowed to freely use the motel recreation facilities such as the swimming pool. Frequently they strike up friendships with motel guests who are unaware they are retarded. Dress and appearance are much like other young people of their age group.

In the area of work the normalization principle is greatly stressed. The main thrust of Cheyenne Village's vocational program is to have residents be able to hold long-term jobs in competitive employment. While there are a few residents who are in sheltered workshop programs, the bulk of the persons in the program are in jobs in industry or working under contracts held by Cheyenne Village.

Not only is normalized behavior practiced, it is also expected of the residents. There is an awareness of the close relationship between expectations and resultant behavior. As a Village statement puts it:

> "In a broad sense, what we do is train a resident to be normal, give him the opportunity to be normal, and expect normal behavior. This philosophy carries over into all parts of the program. If you expect a person to behave and live normally, and continually work towards this goal, you will eventually achieve it. On the other hand, if you feel that a person is retarded and therefore can never be normal, you expect him to be retarded and he will be."

Responsibility

A second theme of the Village's philosophy is having residents take responsibility for their actions. A statement of the program describes it as follows:

> "Many of our residents have grown up in an environment where they were never held responsible for their own acts. Parents protected them, made excuses for them because they were "retarded" and allowed abnormal behavior. At the Village, we force our residents to accept responsibility for themselves. The resident must accept the consequences, either good or bad, of his actions. The resident is placed in a position where no one else will solve their problems, and with counseling, they learn to solve the problems for themselves."

This theme of responsibility is carried out over and over again in a hundred different ways each day. Example: one of the cabins had not been kept clean by its residents. After several warnings failed to get action, the cabin was "quarantined" with a sign put on the door telling the residents they could not sleep there that night. They had to make arrangements with others in the Village for a place to sleep. Another example: a resident got upset with the program and ran away. Although the staff knew where he was in town, they did not go after him. After several days, the young man called his parents and said he was hungry and tired, could they come and take him home. The parents interceded with Cheyenne Village and insisted he be picked up. Since this lifted the responsibility from the resident's shoulders, the staff arranged a meeting with the man's parents. The staff explained that bailing the man out of such situations only increased his dependency in the long run. Together with the young man and his parents the staff worked out an agreement. He would be given another chance at the Village, but if he ran away or did not work hard in the program, he would have to leave and would not be readmitted.

Another example: in spite of all their efforts, one of the residents continued stealing. (The rule on stealing at Cheyenne Village is that the thief has to pay five times the value of the stolen article. If he does not have the money, he has to auction off his possessions.) One day the man was caught stealing a candy bar in a local store. The staff let him stay in the city jail three days. This experience had its effect, and the man has not stolen anything since then.

Long-term Care

A final theme of the program is long-term care. Once a person is a part of the program, there is assumed a long-term relationship between the Village and the resident as long as the resident desires it. If a person needs assistance, he may come to the Village and they will help him--whether it is finding a job, obtaining his legal rights, registering

a car, or talking over a personal problem. This is not a contractual arrangement, but a matter of policy and commitment. At the present time there are only five persons who are in independent living and still in touch with the Village. As this number grows in future years, the form of this commitment may mean developing a geriatric program. This is a long way off. In the meantime, the Village stands ready to assist its former residents in whatever way is necessary to live independently in the community.

These three themes--normalization, self-responsibility, and long-term care--are the basis of the Village's program. They are put into practice with a leavening of common sense, and a highly individualized approach. An approach of firmness that makes sense with one resident might only be frightening to another.

Steps Towards Independence

There is a clear progression of steps from highly supervised living at the Village to independent living in an apartment in Colorado Springs. Residents are fully aware of the progression and are highly motivated to achieve the level of having their own apartment. Being a private program, Cheyenne Village does not have to accept everyone who is referred to them. To be admitted to the program the resident must be over sixteen, have a primary diagnosis of mental retardation and be able to benefit from the program. No profoundly retarded or non-ambulatory persons are accepted. The prospective resident then visits Cheyenne Village and discusses the program with the director. Only if the prospective resident wants to participate in the program and agrees to work hard at self-improvement is he or she accepted, and then only for a 90-day trial period. There is thus established an informal "contract" between the resident and the staff rather than between the parents or the state and the Village.

Step 1: Supervised Living at McLaughlin Lodge

Everyone who enters the program starts in the first step, Supervised Living. This is a period of evaluation and intensive training in five areas: maintenance (personal hygiene, housekeeping, clothes care, food preparation and personal shopping), leisure time activities, socialization (changing "retarded behavior" such as rocking or withdrawing to normal behavior), education, and handling one's own medications. During this six to twelve month period, residents live in a cabin at Cheyenne Village with up to seven others. Meals are prepared by the residents in the cabin on a rotating basis with training by the staff in menu planning, food buying and cooking.

Initially the resident is restricted to the grounds of Cheyenne Village except when there is a group recreation activity or shopping trips. Visits to home are limited to one weekend a month to avoid dependency upon the parents.

When a resident is first admitted, the director describes the person, his background and behavioral patterns at the weekly staff meeting and outlines an approach to be taken with the resident. For example, a new resident may have a history of using sickness as a way of avoiding work. The suggested staff approach might be to not be soft if the resident complains of minor illnesses.

Within three weeks after admittance the resident is asked to select a personal counselor from among the staff. This important relationship with a staff member involves discussing with the resident what he is learning and directing him in areas that need improvement.

Within six weeks of admission a "staffing" report is prepared by the resident's counselor describing the progress and problems of the resident and outlining a program. The program which emphasizes the approach to be used by the staff is discussed at the staff meeting and a consensus reached. The approach is then reviewed in two weeks to determine if it is working and either continued or altered as required. Thus for each person there is a specific, tailored program.

The vocational training program is started immediately with the residents doing work for the motel: maintenance, repairs, maid work, operating the laundry and gardening. Residents work eight hours a day with thirty minutes for lunch and two breaks. Residents are paid from $2 to $45 a week while in training. Since the work is real, there is normal risk involved ranging from using chemical cleaners to using power tools or trimming trees. The risk allowed is determined by the ability level and potential of the resident, but it is assumed that just like in normal life, some risks need to be taken.

The emphasis of the vocational program is purposefully not in skills training. For the vast majority of low skill, competitive jobs which the residents will be able to find, the Village has found that employers prefer to teach the necessary skills. Where residents have the most difficulty is in the social aspects of a job: being punctual, showing up for work regularly, being responsible, being able to get along with fellow workers and one's supervisor, having pride in the job. The staff vocational supervisors for the motel work, therefore concentrate training efforts in these areas rather than in the mechanics of cleaning a room and making beds.

As residents improve in the vocational training, they progress to less sheltered work than the Village environment. Work contracts are arranged with outside employers, and the work is done off the grounds of the Village. Recent contracts include clearing brush and trees in a state park, maintenance and maid service work at a nearby motel, and manufacturing concrete blocks. The work is not done in a sheltered workshop environment but on site. Generally there is a Cheyenne Village staff supervisor at the job. Wages are higher than at the Village, approaching half the minimum wage.

While residents are living at Cheyenne Village there is an active program to introduce them to a wide range of leisure time activities. Many residents have only a limited exposure to recreational activities and they don't know what to do with their time other than watch television (which is frowned on at the Village).

Initially there is an on-grounds program with training in proper social behavior, cooperation with a group, planning activities, organizing time and budgeting money. Physical activities are a major emphasis: swimming, basketball, football, baseball and hikes in the nearby hills.

Off-grounds programs follow when residents have the social skills necessary for going into the community. Being a resort area, there are a wide variety of outdoor concerts, sporting events, and educational trips. Even the more simple leisure time activities need to be structured at first such as visiting the library, going to a pizza parlor, or having a shopping trip. One counselor had a series of evenings where he took a small group of residents to first a Chinese restaurant, then an Italian and then a Mexican restaurant.

The Village's policy on sex is that "there will be no sex before marriage allowed." In discussions about sex with residents, the staff are required to reinforce the Village policy. All women in the program must have some form of contraception; either the pill or an IUD. In practice the policy is enforced at the Village, but there is less control when residents are in the counseling apartments. Of course when a resident is in independent living in his own apartment, sex is his own responsibility.

Because of some homosexual activity, a Friday night dating program was instituted at the Village. Residents are encouraged to "ask out" other residents to the Friday night group activity such as a movie in town or a dance. Occasionally there are sex education classes by the counselors for residents at the Village which mainly deal with the physiology of sex.

Step 2: Independent living at McLaughlin Lodge

To move from supervised living to independent living at the Village, a resident must "ask for his independence" at the weekly staff-resident meeting. These meetings, a unique feature of the Cheyenne Village program, are a cross between a New England town meeting and group therapy. All residents who are living at McLaughlin Lodge and all the staff (including office staff) attend the meetings held in the gym of a nearby high school. Both staff and residents raise any matter which they see as a problem.

It is the resident's responsibility to request movement to the next step at these meetings. Comments are made by the staff in open discussion before everyone. Not all who ask are granted their independence.

At one meeting a woman asked, but the staff was unanimous in her lack of progress: "You still go off and spend time rocking." "Still not neat enough in keeping your personal things." "Needs more enthusiasm in working." Although the comments may appear harsh and embarrassing, they seem to have the effect of urging the residents to work harder in their supervised training so that they can "earn" their independence.

The rewards of "independence" include more frequent visits home, visiting town in the evening, and for those who are doing especially well, living in a housekeeping cabin with only one roommate. The intensive training is eased off and the resident is given a chance to take responsibility for the things he has recently learned. Personal counseling with an individual staff member continues. If the resident has not yet moved to contract work, that is arranged as soon as possible.

Step 3: Training Apartment in the Community

To ease the movement to the community, Cheyenne Village in 1973 opened training apartments in Colorado Springs. The training apartments are in a four-plex in a quiet residential neighborhood. Eight men live in two of the two bedroom apartments, and eight women in the others. All the residents work during the day, most of them in competitive employment. A staff member is at the apartments from the late afternoon into the evenings assisting the residents in the problems of living in the community: shopping, meal planning, where to get a dress dry cleaned. Although residents are on their own, they are asked to check in and out if they go to the store, the library or some other activity.

No longer are there group leisure time activities as at McLaughlin Lodge. Residents are responsible for their own leisure time activities, and staff helps by suggesting opportunities. Heavy emphasis is put on community socialization. Residents are trained to consider and relate to others: neighbors, people at the job, door to door salesmen, people on the bus.

Although the training apartments are in the community, there is still considerable support for the resident: a familiar group with whom he has had common experiences in the Lodge environment, and the constant presence of a staff member.

Step 4: Counseling Apartments in the Community

If a person takes responsibility for himself, makes a satisfactory adjustment to the community and has a competitive job so that he is able to support himself, then he moves to a "counseling apartment". These are normal apartments scattered throughout Colorado Springs. Presently 14 people are in counseling apartments. The staff makes some effort to find apartments in the same neighborhood so that Villagers may visit each other,

but otherwise the residents are on their own. Generally two residents share an apartment, both to hold rent costs down and to provide companionship.

A counselor from Cheyenne Village visits residents in counseling apartments in the evening. Generally the visits last a half hour and the counselor works out any problems that might have come up: advice on paying a telephone bill, finding a neighborhood drugstore, or relationships with a friend or roommate. The counselor varies the visits according to the capability of the residents: some are visited nightly, others only once a week. In addition the vocational counselor continues to keep in touch with the residents. Frequently they lose a job or have difficulties with employers that need to be smoothed out. Although residents are now living in the community, the constant support of the counselors keeps them from regressing or becoming overwhelmed by situations they are not experienced in handling.

Step 5: Total Independence

In the final step of total independence, the staff no longer visits the residents. He is independent and takes responsibility for his own life. A criteria for determining when a person is able to live independently is his ability to ask for help when he needs it. The independent person may come to Cheyenne Village at any time for help. Presently four men and a woman are living in the community on their own.

The Community Home

Not all the residents in the Cheyenne Village are able to progress smoothly along the ladder to total independence. The Village found that some people were no longer benefiting from the intensive training at Cheyenne Village, yet they were not progressing in a way that they fit into any of the other developmental steps. Therefore, in 1974 the Village opened the community home which is a residence for up to five men in one unit and five women in the other.

The home is in a new duplex in a recently built subdivision with a striking view of the mountains. A staff member is on duty full time when the residents are in the home in the late afternoon, evening and morning. Residents are employed either competitively or more frequently on contract jobs which Cheyenne Village has arranged. There is much less emphasis on growth and development, and for the residents in the community home this means less pressure and expectation. It is likely that the community home will be a long-term residence for those who are not able to readily learn to function on their own and need a somewhat sheltered environment.

The community home residents are people who generally are more retarded than the other people in the program or have substantial emotional or behavioral disorders which make independence an illusive goal. When faced with the increased responsibility of the training or counseling apartments, they have become anxious or acted irresponsibly. They cannot handle the admittedly high expectations and pressures for improved behavior. The community home provides them a sheltered environment without such pressures. They are still expected to act responsibly and the development program of the Village and the community program is available to them when they are ready. In the meantime, the community home is for them what a holding pattern is for airplanes.

The decision to move a resident to the community home is carefully weighed and not lightly taken. The staff tend to view such a move as a failure and a dead end. On the other hand, since less is expected, residents often prefer the easy life there, but this may be a reward for inappropriate behavior.

Any human services program is faced with difficult situations. The establishment of the community home represents Cheyenne Village's approach to providing a place in the program for people who have difficulties progressing along the pathway towards independence in the community.

Job Placement and Follow-up

Since the goal of the Cheyenne Village program is independent living, and to live independently requires a living wage, the job placement and follow-up is a crucial part of the program. Three full-time counselors are employed finding competitive jobs in the community and providing follow-up services once a resident is placed.

In addition to scouting new jobs, testing and counseling residents, and arranging job interviews, the counselors actually work alongside the resident on the job to get him started. This takes from one day to two weeks, but in one case the job counselor worked with the resident for six weeks until he became familiar with the job and its requirements enough to do the job unaided.

The counselors stand ready to help residents in times of crisis when their job is in jeopardy. Residents may become depressed and slack off on their jobs; communication between employer and employee may deteriorate; residents may start to be late to work or fail to show up because of upsets in their lives. The counselor then works with the resident, often making daily checks at the job to get things straightened out.

Even with such counseling, residents sometimes fail at jobs. The counselors blame this on "poor attitude" or "laziness". If the resident can no longer pay for his apartment, then he is moved back to McLaughlin Lodge. In order to motivate him to want to hold a competitive, community

job, he is put to work at the Lodge in one of the more unpleasant, isolated jobs. The reasoning is it would be self-defeating to provide him a rewarding job for having failed on a regular job. As soon as the resident is motivated to hold an outside job, new efforts are made to find him a position. As with all the counseling at Cheyenne Village, each situation is handled on a case by case basis with the particular approach designed to fit the individual. If a resident loses a job but it is not his fault (job termination, temporary job), then he returns to a regular crew at the Lodge until a new job can be found for him.

Funding

Operating funds for the Cheyenne Village program come from a variety of sources. They are:

1. Room and Board

   The main source of maintenance costs are welfare payments from the Department of Social Services. For the few clients under 18 there is available child welfare. A small percentage of payments are from parents and from CHAMPUS, the military dependents medical insurance program. When residents move to the counseling apartments, they pay their own room and board from wages they earn at their jobs.

2. Personal and Social Growth

   The principal source of funds is "Title 45" funds, three quarters of which come from the Federal government through the Department of Social Services with the one-fourth matching funds provided by the local ARC. This is the only Title 45 program in the state of Colorado and was worked out by aggressive negotiating by Cheyenne Village.

3. Vocational Training

   Main sources are the Department of Vocational Rehabilitation and the local Mental Retardation Commission. This is a county agency which administers state funds for the retarded.

4. Job Placement and Follow-Up

   Mental Retardation Commission provides state funds.

In addition to these sources, approximately 10 percent of income is derived from the motel operation and a lesser amount from work contracts. Private contributions have been the principal source of funds for capital projects and to a lesser extent contributions have been used to cover operating deficits.

The monthly per person costs are $560 for steps one and two at McLaughlin Family Lodge, $500 for the training apartments and community home, and up to $140 per month in the counseling apartments. When residents are in independent living there are no regular costs for them.

Since the Village has been able to develop multiple, public funding sources, the program is on a sound financial basis providing there are no cutbacks in these sources.

The projected Cheyenne Village budget for fiscal year 1975 is a hefty $296,940 as shown in Table 1. The largest single expenditure, $216,000 is for staff salaries. The budget is programmed for a total of 86 residents actively in the program plus another 12 in independent living status. The gross average cost per resident (excluding those in independent status) is $3,452 per year.

Table 1

Financial Projections

(July 1974 - June 1975)

Housing	$ 46,640
Food	27,500
Personnel	216,000
Miscellaneous (licensing, entertainment, office supplies, etc.)	6,800
Transportation	-0-
TOTAL	$296,940

Number of residents: 86

Cost per resident per year: $3,452

Source: Data submitted by Cheyenne Village

Staffing

To run the program, by July 1974 there were a total staff of 46. This includes a staff of six operating the Lodge for motel guests. (For deployment of staff, see Figure 1.) The program staff to client ratio is approximately one to seven.

With the exception of the Executive Director, Al Bickford, almost none of the staff have had previous experience or training working with retarded people. The majority of the staff are in their early twenties having two or more years of college education. Salaries are low compared to the prevailing wage rates in the Colorado Springs area. A counselor's salary averages $5,750 per year; supervisors average $7,750 per year for a five day, 40 hour week. Although the salary scale is low, the staff are intensely interested in their work and morale is high. Staff turnover is due to marriage, going back to school and occasionally moving on to a better paying job. Many of the counselors hope to continue to work with retarded people in the future.

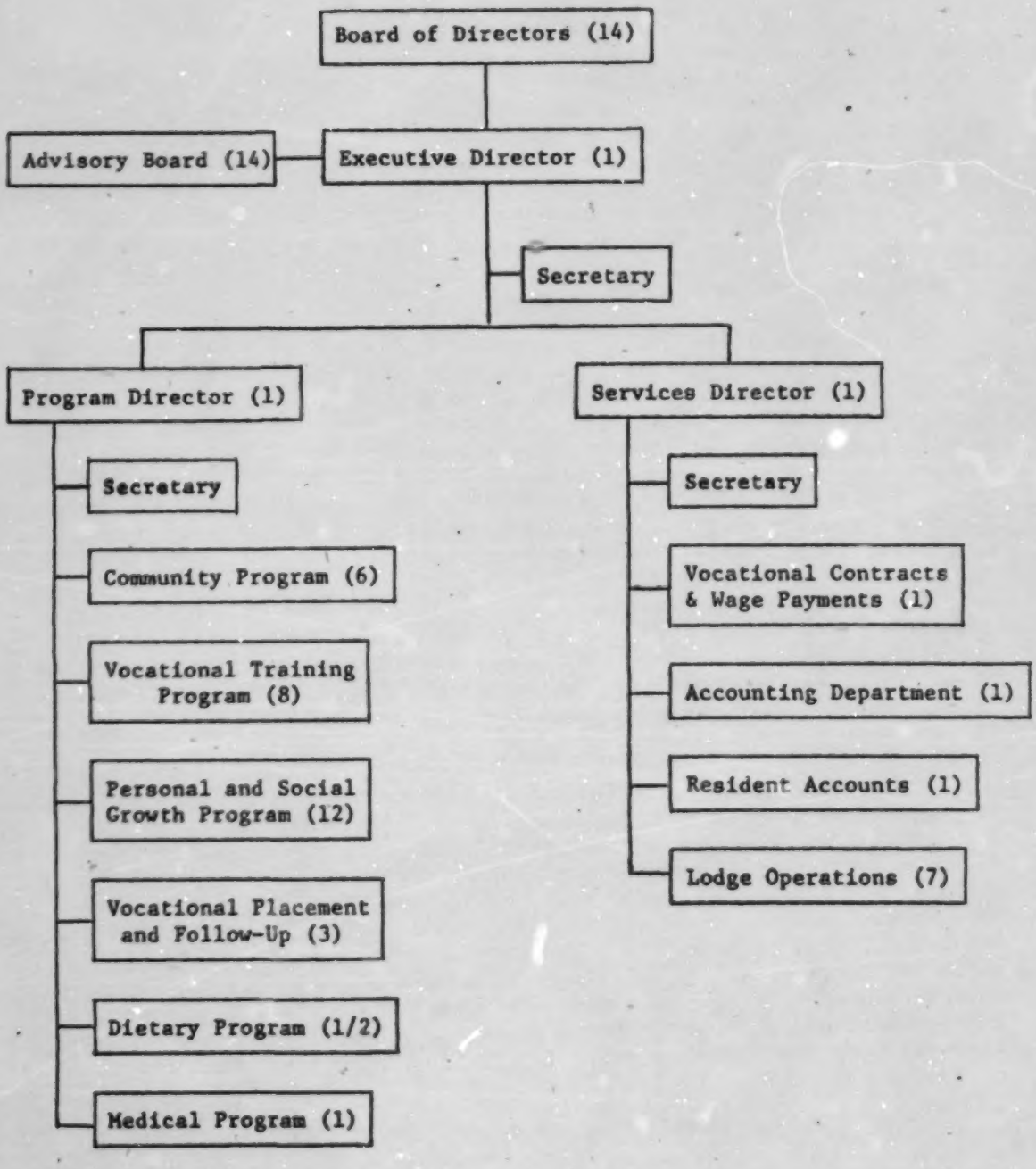
At the Village the counseling staff is divided into two major groups: the vocational training staff, and the personal and social growth program staff. The vocational staff work with the residents doing the motel maintenance work both providing training and supervision of the work. They also do training and supervision on the work contracts which are off grounds. The personal and social growth counselors organize leisure time activities and guidance in housekeeping training such as cooking, keeping the cabins clean and washing clothes. All of the counselors have personal counseling responsibilities with from one to three residents.

The community program is staffed as follows: two counselors at the community home, two at the training apartments and two others who visit residents at the counseling apartments. In addition there are three vocational placement and follow-up counselors working with residents who have jobs in the community helping them find jobs and smoothing out problems as they arise.

A dietician works half-time with residents and counselors mainly in an educational role so that they can learn good dietary habits. The Village also employs a nurse full-time. Her primary function is to work with residents in the administration of medications. New residents, particularly those who have been in institutions, generally are on one or more medications: behavior modification drugs such as Mellarile, and drugs to control epilepsy for those subject to seizures. The Village's objective is first to gradually reduce and eliminate the use of drugs whenever possible through careful observation and review of behavior, and secondly to teach residents to responsibly handle their own medications so that they can take care of themselves when they reach the level of independent living.

Figure 1

ORGANIZATION AND STAFFING



The Board of Directors

While Cheyenne Village's Board played its most active role in the early development stage of the Village, it continues to be active in both policy making and fund raising. The board is made up of 13 Colorado Springs citizens. They include a certified public accountant, vice-president of a local bank, president of a real estate firm, business consultant, wife of an automobile dealer, wife of the Colorado Springs Mayor (herself an activist in the mental retardation movement). One-third of the members have retarded children, only three of which are in the Cheyenne Village program. There are no professionals from the retardation field on the board, although there is an Advisory Board of professionals which meets occasionally to coordinate efforts concerning the program.

When Cheyenne Village first opened, the Board was intimately involved in all major decisions and even some not so major. As the program has grown and the budget expanded, the board has taken a more policy-oriented position. On most matters of program, the Board defers to Bickford. Recent policy decisions include not permitting both partners of a marriage to work at the Village (it leaves two slots to fill if they leave; marital difficulty might make it hard to carry out their duties at the Village), and building two new cabins for residents at the Village. Individuals on the Board also help out in individual ways in raising money, reviewing the budget, and providing real estate advice.

Preliminary Program Results

Since the Cheyenne Village program has been operating for only three years it is too early to be certain what the long term effects of the program will be on the lives of its residents. As of July 1974, there were a total of 73 people actively in the program as follows:

1.	McLaughlin Lodge	30
2.	Training Apartments	16
3.	Community Home	8
4.	Counseling Apartments	14
5.	Independent	5
	Total	73

Another 24 residents had been in the program an average of 8 months and had left for a variety of reasons as follows:

Reasons for Discharge

1.	Parents pulled resident from program	6
2.	Didn't adjust, returned to institution	4
3.	Ran away	4
4.	Left on their own	5
5.	Independent	5
	Total number admitted since April 1, 1971	90

IV. RESIDENT PROFILES

The following case studies are suggestive of experiences at Cheyenne Village.

Gary

Although each of the residents at Cheyenne Village has his own particular style and problems, Gary's ups and downs are in some ways representative of how an individual experiences the Cheyenne Village program. Gary, age 22, came to the Village in October 1972 from Laradon Hall training center in Denver where his behavior had followed a pattern of improvement followed by relapse. At first Gary settled into the Laradon Hall training program and learned janitorial skills. He was able to control temper outbursts that had caused trouble in a sheltered workshop and outside jobs he had previously held.

After a year of dormitory living, Gary was moved to a semi-independent apartment and placed on an evening job as a janitor. However, his work habits deteriorated and he would steal small amounts of cash or soda pop from vending machines--mostly to give to others so that he could be a "big man". When counseled about his poor performance, he would often respond with outbursts of temper in frustration and anger. At one point he punched a hole in the wall and broke up furniture.

The staff psychiatrist at Laradon Hall recommended a new residential placement since the program was unable to give him sufficient guidance. A new setting might also give him a sense of progress. Gary then moved to Cheyenne Village.

At first Gary, who is mildly retarded, rebelled against the tight structure and firm authority of Cheyenne Village. But then he began to respond positively and in both personal and social growth programs and in vocational training. Because of his progress he was placed in an apartment in the community (at the time the training apartments had not been developed), and a job was found for him as a greens keeper at a resort hotel. He was soon fired because of "inability to get along with his peers, poor job performance and laziness." He was placed in a food service job and again was fired because of drinking on the job and not being responsible to his job. His counselors noticed that he was not keeping his apartment clean and he was letting his personal appearance and hygiene run down. Gary also started sleeping with one of the Cheyenne Village women which is against the rules.

When he lost the second job, Gary was moved back to the Village and an intensive program of counseling and training began again. Over the next few months Gary made little progress except that he was able to

control his temper. To encourage him, a temporary job was found at a local hospital. Again his job performance was poor and when the job ended, he was not offered a new job by his employer.

A few months later, Gary was employed at a well-paying janitor's job at a home for troubled boys. Again job performance was poor. Gary spent a lot of time trying to be a "big man" with the boys: racing around in a company car, stealing from a pop machine and buying cigarettes for the boys, flirting with a waitress. Because of this pattern of behavior, he was fired.

Once more back at the Village, Gary decided to run away. The staff knew where he was, but decided to let him experience the consequences of his actions. Within three days he called his parents who asked the Village to take him back.

At this point the staff felt there were three alternatives for Gary: (1) he could leave the program and return to his parents or an institution, (2) he could live at the community home and accept as fact that he would need a highly structured and sheltered environment, probably forever, or (3) he could take responsibility for himself and be in a counseling apartment within six months.

The staff had not given up on Gary, but they felt a concerted approach was needed to make Gary act responsibly. It appeared that all his life he had been able to use his retardation as an excuse to be irresponsible.

A conference was held with Gary and his parents and the situation laid before them. Either Gary took responsibility for himself or else he would have to leave the program. The parents were asked not to be soft with him, but make him face up to his responsibilities.

At the time this was written, the outcome was not yet certain. Gary seemed to be responding to this approach. He very much wants to be able to live on his own and enjoy the fruits of independent living such as owning a car once again. He has the ability to live on his own and to succeed in independent employment. The main barrier to his independence is his personal behavior and attitude which the Cheyenne Village program insists he can control.

Ben*

Ben, an 18 year old Spanish-American, had brain damage at birth, and at the age of 6 months, was discovered to have cerebral palsy, resulting in the impaired use of the right arm and right leg. Ben's score on the WISC, at age 12, was 58 on the Verbal, 55 on the Performance and a Full Scale score of 53. Ben was enrolled in the special education program in

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*Prepared by the Cheyenne Village staff.

the Denver Public School System while in the third grade; and his best performance was equated with fourth grade level work.

Ben comes from a low socio-economic family. He is the eldest of six children. Ben underwent counseling at the Mental Health Center in Denver on the insistance of his mot[illegible] because she was unable to control Ben's constant acting out behavior and his frequent outbursts of temper. His hostility and physical aggression was directed toward not only his family but to peers, teachers, the local priest, and authority figures in general. Ben was evaluated as being impulsive, possessing little control of his emotions, and very immature socially. He was aggressive and belligerant with peers and unattentive, sullen and uncommunicative towards adults. Ben had a very low self-image and was constantly challenging friendships and overtures of friendliness and concern.

When Ben first arrived at Cheyenne Village, he was very sullen, uncommunicative, and withdrawn. He displayed frequent outbursts of physical aggression which were sometimes so violent, it left him physically drained. He openly detested the majority of the staff members and constantly sought confrontation with them.

Gradually, however, through structured guidance and consistent methods of handling, Ben learned to control his temper, and he began using the self-help pattern of behavior provided to him. Within six months, Ben was adjusting well to the program, and progressing constantly in both the vocational and the social growth areas of training. Nine months after entering the program, Ben had achieved independent status at the Village and was a happy, personable, and fairly well-adjusted young man.

Ben is now living in the Training Apartments. His most immediate obstacle to total independence is his immaturity and his difficulty in assessing social situations and exercising social intelligence. However, his outbursts of temper, his sullenness and belligerance, and his confrontation with authority figures are now rare occurances. He holds a job on a community based contract crew, and he is developing into a good, competitive worker. His self-image is growing and so is his desire to achieve. Progressing at the present rate, Ben should be able to achieve Counseling Apartment status within six months.

Terry*

Terry was born of a retarded mother in a state institution for the retarded. The first 19 years of her life were spent in an institution for the retarded. Several attempts were made for adoptions, but all were unsuccessful due to Terry's inability to comprehend relationships of a normal nature.

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*Prepared by staff of Cheyenne Village.

Terry became more and more of an acting out problem at this institution and it was decided that she would either be referred to a community setting (Cheyenne Village) or the State Home and Training School in Pueblo which was geared for acting out, anti-social adult retarded. She entered the program at Cheyenne Village in April of 1971. It was soon apparent that Terry was probably not retarded but was severely handicapped because of her former environment. She had frequent temper outbursts, destructive behavior and phobic fears. She not only was very sadistic with animals and people but also exhibited masochistic tendencies. In short, Terry had no real concept of herself nor any meaningful emotional feelings towards other human beings. More than anything, Cheyenne Village allowed Terry to better understand herself, and develop meaningful experiences through a reality based program with peers and counselors and gave her a structured constructive environment where she was gradually able to relate in an appropriate manner.

An example of this growth was her situation with automobiles and travel. Terry would not cross the street for fear of being run over by a car. She would not ride in automobiles. The staff allowed Terry to respond to these much as a young child would respond. First, by showing her that crossing the street would not endanger her if she looked both ways before crossing, then by driving her around the Village in a station wagon, enabling her to be more secure and develop trust with the individuals who worked at the Village. She then was able to ride outside the Village grounds, eventually moving to the front seat of the automobile. The staff expects that, at some point, she will own her own automobile.

Terry had been rejected many times and attempted to be rejected at the Village. She was extremely hostile and aggressive towards staff even to the extent of breaking bones of staff members. But within the therapeutic milieu, she was not rejected and was able to form meaningful relationships with authority figures. Consequently, her self-image increased, her sadistic and masochistic behavior decreased, and she is now able to relate as an adult.

Terry presently lives in her own apartment in the community and is competitively employed as a dishwasher and responsible for most areas of her life. She manages her social situation very adequately. She has good relationships with her peers and has become a peer to many of the counselors within the Cheyenne Village system.

It is certain that her I.Q. has developed to a normal level but since this is not important in the Village situation, she has not been tested. She will become totally independent within the next year and apparently will have a very satisfying life in the future. She will probably become married and perhaps even have the capacity to bear and rear children.

It should be clearly understood that Terry achieved this growth outside of a psychiatric situation in a reality milieu program.

Bill

Bill is a tall, lanky man of 23 with an extraordinary fondness and way with animals. He denies that he is retarded although he does have difficulty with reading and with numbers. Whatever his disabilities, his abilities are more noticeable: a determination to be his own man; ability to take care of himself including living alone and driving a car; a flair with the electric guitar; and his way with animals which he puts to use in his job at the Humane Society. Bill's dream is to manage a big game park, "like they have in Africa and Australia."

When Bill was growing up, he was trouble for his family. He was one of four boys in an average middle-class family in Pueblo, Colorado. An early report on him commented, "He seemed to have an obsession regarding animals and there is indication that he brought home dangerous animals such as a rattlesnake to the home. When this was taken from him, he would throw a tantrum. There is also indication that he set fire to the family home causing considerable damage. . . .Also, there is some information that Billy would steal animals and money, and he would also lie to his parents and apparently could not relate meaningfully to either his peer group or his parents."

From the age of nine until he was fifteen, he was enrolled in special education classes in Pueblo. At that time his father became seriously ill and was unable to work. The family was greatly relieved when they were able to get Bill admitted to the Grand Junction State Home and Training School.

Bill adjusted well to the state institution. He made friends, was able to learn and soon found ways to pursue his interest in animals. He even was able to have a pet coyote while at the institution. A social worker's report commented, "Bill, with his gangly frame and many interests has become a campus personality. He has outgrown some of the little behavior problems he came with and has adjusted nicely to Carson Cottage where he fits into the group of older boys nicely. . . .In many ways Bill functions quite normally and we see him as a happier, more secure boy than he was when he came to us. He finds satisfaction in his work and appears to enjoy his living situation."

In 1972 at the age of 21, Bill came to Cheyenne Village. He quickly adjusted to life at the Village and in eight months was able to move to a counseling apartment in the community. A job was found for him at the Humane Society which he enjoys but finds that "the pay is too low." Within a few months Bill decided he wanted to live on his own where he could keep pets. The Village found a trailer in a trailer park in Colorado Springs. He is now slowly buying the trailer. He has turtles, a young dog and a bird plus occasional visiting pets from the Humane Society.

In December 1973 with the help of Cheyenne Village, Bill had his legal rights restored which had been abrogated when he was committed to the state institution.

Bill is quite satisfied with his life now. He has a car, is buying his trailer, has a job which he likes and a number of friends. Recently Bill married Connie, who had been living at a Cheyenne Village counseling apartment. They now live together in his trailer.

Although Bill at times has been defiant of Cheyenne Village's overseeing role, he is actually on good terms with the director and several staff members. He comes to them from time to time for assistance and advice--in getting his legal rights, in buying a car, in planning for marriage. Although this is a form of counseling, it takes the form of friendly visits and neighborliness. Bill would very much resent the idea that he is being "counseled".

It is likely that Bill will be able to live a fulfilling, independent life. With Cheyenne Village in the background, he will have a place to turn to if he needs help. Even now he recognizes the need for help in matters requiring reading (like contracts) or numbers (installment payments).

V OBSERVATIONS

The Cheyenne Village program is a unique approach to helping retarded and handicapped people move from dependence to independence. It is recognized by professionals in Colorado as an exceptionally successful program. As a state vocational rehabilitation worker commented, "It's the best program I've ever worked with."

In May 1974, following an intensive on-site visit, the National Commission on Accreditation of Rehabilitation Facilities awarded a three-year accreditation for both the Vocational Adjustment and Social Adjustment programs.

The elements of the program which make it successful have been described previously: the progression of residential steps towards independence, the reality/responsibility approach in relating to the residents, the vocational program including motivation, job placement and continual follow-up and finally the long-term commitment to help former residents remain independent.

What accounts for the success of the program? The elements are several. First, is the committed group of citizens who were not only determined but effective as well. They were able to raise the capital to hire a director and acquire the property. Al Bickford, the director, deserves a great deal of credit both for development of the program philosophy and for his administrative skill in guiding the organization through the initial stages and a phase of rapid development. Furthermore, it was fertile ground. Few choices in community residential care exist in Colorado. The program has been able to expand because of the great need for such services.

Finally, the residents themselves are a factor in its success. They have had the motivation and determination to stick with the program. Once they realized that independence was a possibility and that there were people who would help them get and stay there, they responded to the challenge.

E.

COMMUNITY LIVING PROJECT

An apartment training program for independent living:
A cooperative effort of several community agencies

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APPENDICES

I. INTRODUCTION

The Community Living Project is a residential training apartment in an urban neighborhood where 26 young adults with learning disabilities are learning how to live independently in the community. In a normalizing environment that provides a balance of freedom and support, residents receive training in household management, social expression, constructive use of leisure time, and individual rights as citizens.

Residential counselors provide one to one training in eleven skills areas: money management; meal preparation and storage; grocery shopping; shopping for personal items and household goods; housecleaning and laundry; personal hygiene; transportation and communication; work or activity placement; emergencies, health care, and first aid; legal rights; and interpersonal relationships.

The philosophy that underlies the training is that independence is gained through practice in a realistic independent living environment, so residents live individually in their own apartments practicing the management of their own lives while attending weekly classes and group meetings. The emphasis throughout the training is on taking personal responsibility and making good judgments. Practically, this means that both the staff and the residents take risks in a learning atmosphere where there is freedom to make mistakes.

The program is unique in both its program and its structure. It is a collaborative effort of a number of community agencies, and it utilizes a leased housing facility that enables tenants to have good independent housing at rents within their limited budgets.

II. HISTORY AND DEVELOPMENT

Getting Started

The idea for a training residence for retarded adults was sparked by a social worker at the Salvation Army, who reluctantly had to reject two halfway house applicants because they were retarded. While investigating available residential programs, Betty Arnold discovered there were none in the San Diego area capable of training retarded people to live independently in the community.

Among the contacts she had made in recent graduate school field placements at both the Salvation Army and the San Diego Association for the Retarded were two of her friends whose aid was enlisted in pursuing the idea of organizing a residential training program for retarded adults. These two friends, a social worker with the San Diego Regional Center for Mental Retardation (a diagnosis, counseling and referral agency for retarded people), and a mental retardation consultant with the San Diego Association for the Retarded, shared her concern and enthusiasm for this project.

Together these three women organized a Steering Committee, soon augmented with representatives from a number of community agencies: the Department of Public Welfare, the Department of Vocational Rehabilitation, the Special Education Department of the public schools, the Adult Workshops (sheltered workshops), and the Community Services Section of the State Department of Health (an agency responsible for out of home care of retarded persons). Committee members were carefully chosen for their interest in the project and their commitment to it. Finding these agencies with their focus upon a single goal, was a significant accomplishment. According to Betty Arnold, this kind of broad agency support provides a solid foundation, and the essential first step in creating a community residence. She observes: "To begin to develop a facility, you must check out the climate--the interest groups, the degree of support, the allegiances and so forth. Once that's done, you work with what you have."

Plans for a Halfway House

In October of 1971 the Steering Committee began to work on plans for a halfway house or group home. In the beginning they agreed that one of their objectives would be to train residents for independent living; so they considered training apartments where residents would have maximum opportunity to learn independence. However, they soon abandoned the apartment idea because it was too expensive, and settled instead on the halfway house model that seemed more within their reach. Then, in order to study all aspects of the project before formulating a coordinated plan, they divided into subcommittees to work on finance, program, and licensing.

After four months, they agreed upon a plan for a halfway house, which they presented to the Salvation Army, asking them to sponsor the project. Before the Salvation Army would agree to sponsor the program, however, they required a thorough investigation of existing programs. To comply with this requirement, the program subcommittees launched a campaign of letter writing requesting information on group homes, transitional facilities, and apartment projects for mentally retarded adults. From the information returned, the committee learned, to their disappointment, that while most of the existing programs gave much attention to custodial care and household organization, few if any projects paid attention to the need of retarded persons to develop independence. However, some of the information gathered, which was helpful in providing specific program ideas, was incorporated by the committee in its own plan for a halfway house.

The committee's halfway house plan proposed a program for six to ten residents who would live together in a house in a residential neighborhood with access to public transportation, employment opportunities, and community-sponsored programs for the retarded. The residents would share household responsibilities while participating in a training program to include instruction in cooking, budgeting, housecleaning, laundry, and personal hygiene. Educational courses on such things as sex education, rights and obligations of marriage, first aid, and the use of community resources would be taught at the house, and residents would be encouraged to participate in these individually and as a group. The reward for successfully learning skills would be opportunities for "Solos in the Community"--that is, times when each resident would live alone for short periods in preparation for living independently. The theme throughout the program was the right of the retarded adult to exercise personal freedom in developing responsibility to himself and to others. To promote personal freedom, residents would be allowed to manage their own time, money, and household with as much independence as each of them was capable of handling.

Fortunately, the Salvation Army did agree to sponsor the project. The sponsorship included financial support both for a part of the program and for the salary of the part-time coordinator of the project, as well as their commitment to aid in obtaining additional funding.

Implementing the proposal required the skills of all subcommittees. The Finance Committee wrote many letters and grant proposals. The Licensing Committee obtained information about the requirements for obtaining a license, and the Program Committee continued to work out the details of the proposed program. Betty Arnold described the obstacles met by these committees:

> As you might guess, our biggest problems centered around finding a facility and the money to operate it, both at the same time. We looked at several large homes that were for sale, but found ourselves in a dilemma: if we had more than

five residents (ideally ten) so that the resident's income could meet operating expenses, the cost of the alteration to meet fire safety requirements (for the license) would be prohibitive; if we had five or less, resident's income would not meet operating expenses, even though alterations might not be required--and what could we demonstrate with only five people, when there were hundreds needing our service? Oh, for someone to donate a facility--preferably an eight or ten unit apartment building.

Obtaining a Building

In June of 1972, somewhat discouraged with the search for money and a facility, the committee found its attention directed to an article in the Mental Retardation News describing the use of Housing and Urban Development (HUD) funds for housing of mentally retarded persons in Michigan. Since one of the HUD programs in San Diego was leased housing, the committee went to the Public Housing Authority (PHA) to request an 8- to 10-unit apartment building. Since all prospective residents could individually qualify for such housing on the basis of their low incomes, the Social Service supervisor for the PHA, (a former probation worker with experience with the mentally retarded) was able to give her aid and support to the committee's request, which was then channeled through the PHA Advisory Committee and the City Council.

The advantages of leased housing obtained through the Public Housing Authority were several: there would be no large investment in a facility; residents would have to qualify individually thus creating a normalized need for suitable housing; and they would have good housing at rents within their limited budgets; residents could live more independently in apartments than in a halfway house; residents would have the opportunity to transfer to other leased housing upon graduation from the project; there would be no need for a license since residents would live in their own apartments; the model could be easily duplicated by others which supported the Steering Committee's goal of demonstrating a new replicable program. So, plans for a halfway house had now become plans for an apartment house, a return to the preferred model.

By August 1972, the request for an apartment house had been approved by the PHA, and in early September the Steering Committee was offered their choice of three buildings. The committee selected an eight-unit building centrally located in a residential district, within walking distance of the local buses. Meanwhile, a small demonstration grant of $4000 from United Way was approved to help in payment of staff salaries, and another small fund was received for rental of furniture. Since the PHA wanted the units to be occupied within two weeks, the committee had to work rapidly to screen both residents and staff.

Selection of Residents

Since the committee members already had contacts with many mentally retarded persons desiring more independent living, applications came pouring in as soon as the word was spread. Applications were screened by committee members from the Association for the Retarded and the Regional Center, who had had prior experience in directing referrals.

Residents were selected according to these requirements as stated in the recent Community Living Project brochure:

> To qualify for the project, the developmentally disabled individual must be at least eighteen years old, eligible for low income housing under the San Diego Housing Authority, and have sufficient income to meet his own living expenses. Tenants are selected from a waiting list of those who show potential for independent living and who have the communication skills necessary for the training programs provided in the project. Tenants must be willing to prepare for and participate in a suitable program of daily activity in the community.

To focus the program, the Selection Committee made the decision that the residents' primary disability should be mental retardation.

While the Public Housing Authority allows the Community Living Project to do their own screening and selection of residents, the residents may not have a combined public assistance and employment income of over $5,100 per year.

Ten residents were selected: five men, and five women, between the ages of 18 and 35. Four would live alone in one-bedroom units; four would share two-bedroom units with roommates; and a married couple would occupy one unit. This would leave the remaining unit for the resident counselors. A paper on the project described the residents chosen:

> The tenants were all mildly or moderately retarded, but had come from different settings. Three (including the married couple) had been on their own for at least three years, but had managed poorly, living in isolation or exploitation. Two had been institutionalized--because of no other place to go. One had been left by his mother in a downtown skid-row hotel, afraid to leave his room or to let anyone in. The others had always lived with their parents, although one man was 35 years old.

Through experience the committee has discovered that in order to succeed in the program residents must not only want a place to live, but have a sincere desire to participate in a training program that leads to independent living.

Selection of Resident Managers

The Salvation Army screened applications for resident managers, who are now called resident counselors. These applications were obtained through a newspaper ad. Although they would have preferred to find a couple with previous experience in an apartment program for the retarded, they found none available locally and settled for applicants with related experience. They felt fortunate to locate Mike and Patti, a young, enthusiastic couple in their mid-twenties who had worked as houseparents in a private residential facility for the handicapped and retarded. Most importantly, Mike and Patti shared the committee's concern for developing a program that would effectively train for independent living.

Moving In

On September 24, 1972, almost a year after the planning had begun, the tenants and the resident managers moved into the apartment building quietly, unannounced to the community. Betty Arnold explains how this worked:

> We moved in quietly without announcement or sign. We believed that our tenants should and could be absorbed into the community and that it could be done more easily without fanfare or label. This was born out in our year's experience there. To our knowledge it was never known in the neighborhood that our tenants were any different than their neighbors.

The first ten months of operation were full of growing pains. Program plans had to be tailored to fit the needs of the individual tenants, and expanded to include things unplanned for. Tenants' goals had to be tactfully communicated to employers, workshops, and agencies. Additional funds and staff had to be obtained. Through all of this, however, the program was relatively successful, and the response of parents and community agencies was very cooperative and supportive.

Expansion to a New Building

When the waiting list had grown to 26 applicants, the Steering Committee, which was now functioning as an Advisory Committee to the Salvation Army's Central Advisory Board, decided to submit a request to the Public Housing Authority for additional units. Coincidentally, a building developer was at the same time requesting that the Public Housing Authority accept his recently completed 28-unit apartment building for the leased-housing program. The apartment building was located in a quiet residential neighborhood, convenient to transportation and shopping.

Since the Public Housing Authority had now received housing requests from other special-interest groups, they decided to establish a policy for special use of leased-housing units before honoring the request. The new

special use policy limited the number of PHA units that would be allowed for special uses, required demonstrated success of the requested use, and exacted responsible management of the property and monies. The first apartment unit met the demonstration requirement, and the Salvation Army, with its creditable and long-term records of responsible management, was found acceptable as project manager. The Advisory Committee's request for the larger unit was honored, and the project's use of the 28-unit building was approved.

Soon, expansion again required the aid of the Selection Committee in screening an additional staff person and new residents. With the aid of lessons learned in previous selections, the committee accomplished its task swiftly and successfully.

The new apartments would provide brand new individual apartments for each of the twenty-six tenants (two apartment units would be for the resident managers), and it was hoped that the tenants would be sufficiently inspired by the new quarters to keep them neat and attractive.

The Community Living Project Apartments

The Community Living Project, constructed in 1969, is a 28-unit, modern apartment building, unlike typical public housing with its institutional look. The apartment, like many other newly-built apartment complexes in San Diego, is a two-story walk-up with individual stairways leading to groups of six or more apartments in various sections of the building. The exterior is stucco with wood trim. While not an architectual masterpiece, it is certainly not unpleasant.

The apartments are one-bedrooms and studios with small, but complete kitchens and wall-to-wall carpeting and drapes. For the most part, furniture is rented from the Salvation Army at a small monthly charge; however, residents who wish to may purchase the furniture rather than rent it.

The building also contains a social room. It is large (about 20 x 30 feet) and cheerful, with wall-to-wall carpeting. At one end of the room is a fireplace with deep carpeted stairs that function as seats. There are also a ping-pong table, a record player and records, a coke machine, a telephone, and a small table with chairs. The room is used for weekly group meetings as well as occasional recreation and large parties. An adjoining small room contains coin-operated washers and dryers.

Since the Public Housing Authority does not allow unrelated tenants to reside in the same apartment, all residents have single units to themselves. They have decorated their apartments in individualistic styles that reflect their personal tastes, some with more flare than others. Almost without exception each apartment has posters and pictures, calendars, clocks, and bulletin boards. Some have further decorated the walls with tapestries or other wall hangings, and others have lined walls with bookcases filled with books. All residents have either their own television,

record player, or radio. The Housing Authority has a "no dogs or cats" rule, so many tenants have birds or fish. Hobbies are also apparent. One young man has partially furnished his apartment with furniture and lamps of remarkable quality which he has made himself. Another young man collects antiques and has included them in his apartment decor.

On two sides of the apartment are towering rows of Eucalyptus trees which give the building its name, "Eucalyptus Gardens." Since very few residents have automobiles, the large parking area which flanks the building goes virtually unused. In a corner of the parking lot is a small trailer which serves as an office for the Project Coordinator, Linda Stende.

The surrounding neighborhood is a quiet, well-kept one of middle-income families in moderate sized homes, scattered with a few other apartments. Jobs and major shopping are within a couple of miles, and easily accessible by local buses which stop four blocks from the apartment.

III. PROGRAM

Philosophy

The philosophy of the Community Living Project is that independence is learned through practice in a normalizing environment that provides a balance of freedom and support. To make this purpose a reality, the staff works to make the living experience as realistic as possible. Staff allow residents to manage as much of their lives as they are able, while they learn at the same time to take risks and make mistakes. An underlying belief that the mildly and moderately retarded adult is capable of self-responsibility and self-determination is evidenced in the training program's emphasis on individual responsibility and good personal judgment. Linda, the Project Coordinator, says: "Making judgments is crucial to making it on your own. We try to teach the people here how to do that." Accordingly, the program is transitional and voluntary, further demonstrating the staff's belief in the residents' ability to learn how to live independently.

Apparent--though not explicit--in the project's stated philosophy and goals is the element of personal responsibility. The goals as set forth in the project's brochure are:

> "...to learn to practice basic living skills which will enable them (the residents) to live independently at the level acceptable to themselves and others with whom they come into contact."
>
> "...to expand and enrich each tenant's potential to move into and become a contributing member of the larger community."

Expectations and Rules

To find--and maintain--that tenuous balance between "freedom" and "support" is not always easy for the Advisory Committee and staff. A few months after the opening of the first (the smaller) apartment, the staff began to debate the question of just how much of a training program they could impose on people who lived in their own apartments. The staff had started with the original "group home" idea, which would have made it far easier to involve a household in a group training effort. But now, finding themselves in an apartment-living project instead, they had to rethink their approach--particularly when the tenants began to balk at fulfilling the program requirements. Although tenants had been told beforehand about the training requirements, neither they nor the staff had been clear enough about the expected level of involvement. So they developed an "Expectations Booklet" based on one such brochure prepared by a Pennsylvania program called "Transitional Services." The "Expectations Booklet" lists the tenant's responsibilities in taking care of his/her household, in attending to financial matters, and in fulfilling his/her

responsibilities to the apartment community as a whole. When a tenant enters the training program, he/she enters into agreement with the staff by signing the contract on the back page of the booklet (See Appendix A).

In addition to the expectations for accepting personal and household responsibility, tenants must come to the weekly tenant meetings, and keep appointments with counselors for training in cooking, cleaning, shopping and budgeting. They must also be engaged in a daytime activity.

While contact with parents and families is expected to continue during the training program, dependence on parents is discouraged. Residents are allowed leave from the project for only one weekend a month. This rule was established after one mother arrived at the project with her daughter and did all her shopping for her each week.

In order to discourage disruptive parties that would disturb neighbors, tenants must request permission for parties of more than six people. Since the Salvation Army does not condone drinking, it is prohibited in the social room, both for individuals and groups. However, drinking by an individual in his/her own apartment is the tenant's own business, and the staff imposes no restrictions unless it is brought to their attention through some other means.

While there are no rules for "lights out" or bedtime, no visitors of the opposite sex are allowed to remain in the apartments after 11:00 p.m. on weeknights and 12:00 p.m. on weekends.

Staff and Their Roles

Besides the Project Coordinator and the Advisory Committee, the staff of the Community Living Project is composed of three live-in counselors. The three Residential Counselors, originally known as Resident Managers, reside at the Community Living Project in their own apartments. Mike and Patti, a young couple in their mid-twenties who hold two of the counseling positions have been on staff since the beginning of the project. Melanie, a single young woman, has recently joined the staff, succeeding a young man who had joined the project at the time the project expanded to its present 28-unit building. While the counselors' main responsibilities are to provide basic skills training, they are also available five evenings a week as teacher, advocate, counselor or friend, to assist residents in handling problems of any magnitude. When asked to define their roles, they said they also saw themselves as "nosy apartment managers," a description that somehow aptly fits their delicate role in providing support and freedom, while at the same time attempting to see that rules are obeyed. In developing training programs for teaching skills, and in relating to the residents, they work closely with the Project Coordinator, Linda.

Linda's original job as Staff Social Worker was created about eight months after the project was under way. The intention of the Advisory Committee had been to provide training and group counseling, while relying on the Welfare Department for direct counseling services to clients. They found however, that while the Welfare Department was most cooperative, it could not provide all of the services needed by the tenants in the new training program. Therefore, to aid in direct counseling of tenants, to facilitate communication, and to coordinate the tenant programs--within the project, with other agencies, with employers, and with parents--they decided to hire a full-time staff social worker at the earliest possible opportunity. So, in June of 1973, when funding became available, Linda was hired.

Within the past year, with the resignation of the former Project Coordinator, Linda's position has been upgraded to Project Coordinator. Although Linda's position requires a master's degree in social work, the educational requirements for the Residential Counselors are not so important as their understanding of and ability to work with mentally retarded persons.

These four staff members work continuously, in all aspects of the training, to provide the support necessary to motivate and encourage residents to learn all that enables them to live independently. The staff finds this no small task. While actual skills training can be developed in a fairly concrete way--with certain adaptations to the individual--there is "no magic formula" for providing a good learning environment. Staff members get together frequently formally and informally, to discuss individual tenants in an attempt to develop a coordinated, consistent manner of relating to residents. The staff attempts to accent strengths and to "build in" successes in the training, which will aid the tenants in avoiding situations in which they build up failure after failure.

To provide tenants with the freedom required to develop independence, staff does not provide 24-hour, or weekend coverage to handle crises; nor do they always intervene in the tenants' management problems. On at least one weekend occasion, tenants called in police to handle a dispute in which residents failed to make their own decisions. On several occasions, staff has allowed electricity and telephones to be disconnected for non-payment of bills, and the resident has learned the hard lesson of having to pay an additional installation fee.

Daytime Activities

Tenants are expected to participate in a meaningful daytime activity. such as job, school, workshop, activities program, or volunteer program. This requirement, while somewhat flexible, is intended to promote tenant involvement in the community.

Eleven of the 26 tenants have competitive employment in a variety of positions. Only three, however, have held their jobs for a period of a year or more. Although staff and committee members put much effort into obtaining suitable employment, and have in some cases provided for special training desired by tenants, work remains one of the project's most difficult issues. Tenants complain that their work is boring, and that low pay offers little incentive to work--and so, some prefer to stay at home and loaf. One confirmed anti-work resident, a young man who collects antiques, went before the Screening Committee with a well-defended case for not working, and was given permission to occupy himself as he wished during the day. A few tenants have jobs that are both interesting and meaningful to them: one woman, who wanted to work with animals, is very pleased with her job at a boarding clinic for dogs; another, who enjoys working with children, is happily and usefully employed in a preschool.

Training Program

Immediately upon moving into the apartment community, tenants begin to take personal responsibility for themselves and for the management of their households, receiving whatever measure of support and aid they need from the residential counselors. For most tenants this means accepting more responsibility than they have ever had before, and while this practice is crucial to learning independence, the adjustment is a major one. For many, just admitting that there are certain things they don't know, or don't fully understand requires a period of trust-building with their counselors. As counselors are increasingly able to demonstrate understanding and support, tenants respond with increased cooperation and readiness with respect to the learning process.

The training encompasses a broad range of practical and social skills, many of which are taught in individual sessions. The curriculum includes eleven skills areas: money management; meal preparation and storage; grocery shopping; shopping for personal items and household goods; housecleaning and laundry; personal hygiene; transportation and communication; work or activity placement; emergencies, health care, and first aid; legal rights; and interpersonal relationships. The instruction takes place in three basic individual sessions, supervised shopping trips, and group meetings. All tenants sign up for three half-hour training sessions per week in money management, meal preparation, and housecleaning/laundry. This instruction is given by a residential counselor who meets with each tenant in his or her apartment at an appointed time.

Money management is a training session taken by most tenants throughout the duration of their training. Learning to cash and deposit checks to a bank account, and to allocate amounts to budget items, requires repeated practice. For some, this begins with learning the denominations and value of money. To overcome budgeting problems, many tenants use an "envelope system"--large envelopes labeled with pictures or words for receipts, and smaller, similar envelopes to hold money for each budget item. Budget-expense books provided by the bank are used for recording all expenditures,

and for preparing a budget for the coming month. An attempt is made to familiarize tenants with paying bills by both cash and check or money order. Learning how to file an income tax report is one of the last stages of the training. One very practical financial relationship a tenant must maintain on a monthly basis is with the City Housing Authority.

Meal preparation, a popular training session with most tenants, requires mastering the complex skills of planning, reading, measurement, coordination, and timing. Although teaching aids, such as picture cookbooks, taped recipes, specially marked measuring cups and timers, make the task somewhat easier, it is still a challenge. For this training, tenants select a recipe a week for a favorite food. In the project's beginnings, counselors attempted teaching the preparation of full meals, but they have since reduced initial requirements to the mastery of one main dish; then, they work gradually to the preparation of a full meal. Lists of mastered recipes are entered on a calendar, along with notations of the tenants' progressing abilities. Menu-planning, nutritional concepts, proper use of kitchen applicances and tools, cooking measurements and vocabulary, as well as food storage, are all essential to meal preparation, and every phase requires making judgments. An especially difficult judgment for tenants has been in determining whether or not food is spoiled and must be discarded.

Shopping trips for groceries and personal items are first made with counselors. Tenants learn how to shop for appropriate quantities, ask for help from clerks, and shop for bargains; they then do it by themselves or with a friend in the apartment community.

Cleaning and laundry lessons are the least liked of all. In house cleaning the counselor begins by finding out what the tenant can already do. Once it is discovered what cleaning skills need the most work, the counselor assists the tenant with the cleaning. After this, the counselor only checks it over; finally, the tenant does the job by him/herself. At first it seems best to concentrate on one thing at a time: sweeping, dusting, mopping, vacuuming, or scouring sinks. Weekly assignments are to work on one main area while doing a superficial overall job on other things. Each assignment is followed up the next week. The most difficult chores for most tenants are defrosting the refrigerator, and cleaning the oven, but there are some tenants who find it all difficult; for them, the counselor is available twice a week. By comparison, laundry seems an easy task--consisting simply of sorting clothes, and learning to use soaps and bleaches. As with all other instruction, the class is excluded from the tenant's schedule as skills are acquired, and the tenant assumes full responsibility for his or her own cleaning chores.

Evaluation

The staff evaluates each tenant every three months to determine his/her progress in each skill area. A "success booklet" containing pages for each skill area--broken down into specific tasks--is scored and tallied, then

discussed with the tenant. Certain difficult tasks receive double points. A sample skills evaluation, "Transportation and Communication," consists of the following items: can use buses; can call bus company to get directions; can read bus schedules; can walk to places in neighborhood; follows pedestrian rules; can ask and follow directions; can call a taxi, can read a city map; knows how to travel outside San Diego (by bus, train or airplane); knows how to use a telephone (scores double); knows home address and phone number or always carries it (scores double); can read important words; knows how to write a letter and mail it. Tenants vary greatly in their ability to acquire these skills, and in the speed with which they are able to progress. Periodically, the staff and Program Committee work together to refine the evaluation standards so as to render them more sensitive and more readily applicable to individual tenants, and to make the scoring techniques more consistent.

Tenant Meetings

The Tenants' Meeting is a weekly multi-purpose meeting attended by the entire apartment community. The twenty-six residents and the staff gather in the social room for a brief business meeting, followed by an educational presentation that culminates in small group discussions.

The business meeting takes up and resolves administrative matters affecting the community. Agenda items are initiated by staff and residents alike. In one recent meeting, tenants made recommendations about changing the time and format of the meeting itself. These recommendations were considered by the staff who returned to the meeting with two lists: one of the tenant recommendations and another of staff responses to the issues. The majority of the suggestions were acted upon, and tenants were pleased. From their active participation and their ability to challenge issues, one would deduce that tenants are putting into practice what they have learned about choices and alternatives.

Educational programs include several subjects: emergencies, health care, first aid; legal rights; interpersonal relationships; sexuality; community orientation; safety. Many of these are presented--or experienced in innovative ways. In learning about fire safety, a safety officer set a fire in the alley, and the residents practiced using a fire extinguisher to put out the fire. In learning about decision-making, tenants role-played scenes with door-to-door salesmen, "borrowing" neighbors, and neighbors playing loud music. A recent extended program item was a course on sex education developed by the project staff. This program included guest speakers and films, as well as staff and volunteer presentations. Goals outlined in the course were: improved self-esteem and self-acceptance; knowledge--factual information about sexuality; seeing alternatives --choices of ways to live in the society; awareness--increasing insight about their own sexuality and its effects on both themselves and those around them.

The small group discussions that follow the educational presentations are designed to enlist even more sharing, participation, and discussion. Three groups of ten each meet in apartments for discussion of the evening's topic. Each group has a resource person, either a volunteer from a community agency or a staff member, who aids in the discussion. A small group which met recently following one of the sex education sessions spent an hour sharing attitudes towards sex and marriage; the repeated emphasis was on the availability of alternatives and the necessity of making responsible choices.

Sense of Community

While the planned purpose of the Tenants' Meetings was a type of group counseling affording tenants an opportunity to express themselves in a group, the Tenant Meetings seem to have achieved an even more noticeable result--a sense of community. In these meetings, one is keenly aware of the network of friendships and relationships evidenced by the mutual support and sharing amongst the community members. This high community morale is a product not solely of the meetings, but also of the day-to-day relationships that germinate and grow as a result of interaction with neighbors who share one another's experiences in myriad ways.

Recreation and Leisure Time

According to the Community Living Project, one item in an inventory of skills for independent living is constructive use of leisure time. Therefore, the program does not emphasize planned group recreation. Rather, the thrust is in getting tenants involved in recreational activities of the larger community. Indeed, one of the evaluation items is: "Does the resident know where in San Diego to have fun?" However, for those who choose them, there are planned group recreational activities. Local sporting events are favorite group activities. Going to movies seems to be a favored activity of small groups of two and three, as does watching television--or simply socializing in someone's apartment.

IV. RESIDENTS

General Description

Twenty-six adults between the ages of eighteen and forty-four live in the Community Living Project: sixteen men and ten women. The majority of the residents are in their early twenties, while three are over thirty-five. Backgrounds are varied: prior to moving to the apartments, 15 lived with parents or family; 4 lived in the community but were not doing well; 4 were in institutions; 1 was in a board and care home; and 1 was deserted (one vacancy at time of tally). Six are from minority groups. All have a primary diagnosis of mental retardation, and some have muscular dystrophy, epilepsey, diabetes, or cystic fibrosis.

Individual Profiles

The following sketches are representative of some of the apartment residents. They are not intended to be comprehensive as they are developed from interviews with the residents themselves.

Stephen

Stephen is a tallish, thin young man of twenty-five with a clean-cut and shiny appearance, who appears bashful and somewhat tense. Along with two brothers and one sister he grew up in the South Claremont area of Southern California, in a house that overlooked the bay. His father works for a San Diego utilities company, and his mother does not work outside the home.

He is new to the Community Living Project. Before moving here he lived at home with his parents and worked. For two years he worked as a janitor for the U. S. Post Office; he liked the job, mainly because of the benefits be received from the Federal government. For a time he also attended a training center where he learned pottery, and carpentry, which he enjoys a great deal. His apartment is partially furnished and decorated with these fine handcrafted wares. Besides carpentry and pottery, his favorite pastime is reading. He devoures books on Alaska, and subscribes to U. S. News and World Report (which he likes better than Time), Sports Illustrated and The Plain Truth magazine, a political-religious periodical.

At present, Stephen does not have a job, although he would like to get one with the Fish and Game Department, or with the Forestry Service, because he enjoys the out-of-doors and animals. His Vocational Rehabilitation Counselor is helping him to find a job, and has located a gardening job he thought Stephen might like; but Stephen doesn't like the idea. He thinks gardening is a dirty job.

Stephen likes all his new friends at the apartment, although he often feels shy about getting to know them. He also likes what he is learning. He is learning to cook--mostly spicy things like pizza, spaghetti, and pork

chops, for which he is acquiring a new taste. He smiles shyly and says: "I'm really beginning to like it!" He is proud of his culinary accomplishments--especially since he had not been allowed to cook at home. His father didn't think men should cook, so he had cooked only TV dinners at home. He feels he doesn't need to learn too much more about cleaning his apartment because he cared for his own room at home; now he continues meticulously to clean things, dusting his furniture daily, and polishing it once a week.

What Stephen experiences as being different, now that he lives in his own apartment, is that he is "calm--has no emotional problems"; he used to be tense because his mother and father were not considerate of him.

Patsy

Patsy, twenty-seven, is a short, slightly overweight young woman who seems to be generally very serious, although given to periodic bouts with the giggles. She has lived at the apartment community for about eight months; prior to coming here she lived with her mother, with whom she did not get along well. She has one brother and four sisters. She feels as though she has had a rough life--practically raising her sisters while her mother, who was an alcoholic, was drunk most of the time. She went to seventeen different schools, and lived often with the fear of running out of food, or being thrown out of her house, both of which apparently happened on one or more occasions.

She really likes the apartments, and feels that here she has the freedom she has wanted for a long time. She says: "I've always wanted to have a life of my own. Home was very limiting--no friends or anything." Here she also has friends. (There is only one person she does not get along with.) She also has a boyfriend, a young man who also lives here and is very good to her. She feels the staff is particularly helpful and sharing.

Although she knew how to cook and clean before coming here, budgeting was a real problem. She used to be always broke, and now she is learning to budget. During the day she is in an occupation program, but would like to work with pre-school children. Her nerves are calm, now that she doesn't have to worry so much about everything.

Willie

Willie is a young, black man of twenty-four, who is rather tall and thin and neatly groomed. His perpetual broad smile is most friendly. He has a good deal of difficulty both with his speech and his ability to express himself.

He used to live at the San Diego YMCA, and has been here for several months. Before that he lived in Stockton, California and in Oregon.

He works at the Miramar Naval Air Station where he earns 2.73/hr. doing janitorial work, serving food, and washing dishes. He likes the job, and feels it pays well.

His best friends are several of the people at the apartments, and some people at his church.

What he is learning most about at the apartments is budgeting, although that's difficult because he likes to spend all his extra money on clothes. He has some difficulty with cooking. He says: "Mike is on my tail about cooking because I miss my appointments." He defends himself by saying that he is just tired when he comes home, and doesn't feel like cooking. He does want to learn though, and to graduate. That's important to him.

Frank

Frank is a young Chicano man, who is tall and lean, and rather charming. He explains that he is not really Chicano, but actually five breeds, and you are off on a colorful tale about extraordinary experiences and achievements.

He boasts that he has a very large family of five sisters, nineteen brothers, eighteen cousins, an uncle, and a great uncle who was Chinese. His parents died when he was very young--his mother when he was six years old, and his dad when he was only three months. He lived with his grandparents for several years, and then in a series of foster homes. His last home was in Arizona, where he graduated from high school in 1967.

Frank heard about the apartments through a former girlfriend who still lives here. He used to come here to visit her, and decided it might be a nice place to live, so asked about it. Eight months ago he moved in. What he likes most about the apartment now that he is here, is that it is cheap, and he can save money. He's also learning how to make his grocery money last the entire month. What he doesn't like are the group meetings which he finds boring because they always talk about the same things.

He used to sell cosmetics for a living, but now he is doing something he likes far better. He is the Third Assistant Cooking Instructor for the Linda Vista County Education Project that has fourteen cooks. He knows he is an R.O.P. Career Intern, but he is not quite certain what that means. Anyhow, what he does at Linda Vista is cook. He likes making a Spanish omelet with four eggs, or barbequed ham and beef sandwiches with grilled cheese, or vegetable soup. He grins from ear to ear and says that he is the "master cook besides the teacher."

He has a great many hobbies: karate, art, bike riding, and, of course, cooking. He dons a brightly colored, red and black oriental coat called a Kua, and says that he has a brown belt in karate and judo. His girlfriend

doesn't like it though that he practices karate and stuff so much. She thinks he acts nutty. Oh, and by the way, did I know that the reason he found the sex stuff at the meetings boring was that he used to be married. The staff doesn't believe him, but he was.

His only problem is that he sometimes gets really angry, particularly when he is provoked, and that happens most often with his girlfriend. Then he gets mean. Sometimes he also feels confused, and that gets him "riled up," but he doesn't "feel guilty about it." As a matter of fact, he has no shame or guilt about anything. He feels he has a high intelligence, because he acts that way, and because on tests it shows that he likes biology, geology, world history, science, and algebra. His grandmother told him he was retarded, but he thinks "people who say that must be the same way."

He muses, and says he might go back to Arizona, or to "a state of shock." He laughs loudly at the joke, then I feel free to laugh too.

Their Parents

Many parents are actively involved with the project and work cooperatively with the program. They attend periodic meetings to discuss the project's methods and goals, as well as the problems and progress of their children.

For some parents the project has been a learning process for them as well as for their children. While communicating with the staff has helped them to understand why the project does things the way it does, it is not always easy to see their children taking risks and making mistakes. They try hard to understand that it is not good for the independence of their children to come home more often than one weekend a month, but still they would like to see them more: it is a big change to have a child who has perhaps lived at home for as many as thirty years suddenly move out on his/her own. They worry too about their children's loneliness, sloppiness, or abilities to remember medication or baths. One parent confessed that she tries very hard "not to be a mother."

Nonetheless, most parents have responded to the program very favorably. They observe that their children have made noticeable strides in both management and social skills. One couple responded: "It is a great program. It could not have been done at home." Another who was impressed with the speed of the program, said: "We never had any conception that there could have been so much good change in such a short time."

According to parents, the most noticeable effect of the program has been in developing increased independence and confidence. Tenants demonstrate this in their individual ways--by thinking more independently; sometimes in disagreeing; by handling social situations more aggressively; by setting their own schedules, and by developing new interests. However, whatever the measure of independence, parents all observed that their children have achieved a new level of confidence and pride in themselves. For many parents, particularly

those of retirement age, seeing their children develop their own abilities to care for themselves is both relieving and satisfying.

Graduates

Within the past six months four residents have graduated to independent apartment living. The graduates have all been in the training apartments for a year and a half to two years, and have demonstrated to the staff and the Advisory Committee that they are able to manage their lives independently with a minimal amount of support. Three have moved to other apartments in San Diego and maintain their friendships and contact with the staff. Two of the three have transferred to other Public Housing Authority apartments, the other one has a regular apartment. The fourth graduate has married and moved to Modesto. Staff visits with graduates once or twice a week in the evenings according to the needs of the graduate. Usually the visits are for half an hour. What graduates request most often is advice in the payment of a bill or some other financial matter.

Staff has observed that at least one of the graduates now seems to spend more time at the apartment community then he did when he lived there. The community of friends, and the supportive atmosphere continue to be very important to him. Graduates also find means of insuring the contact and support of the staff by eliciting aid with matters they handled well before graduating. So, while graduation is a source of pride and accomplishment, that step is also an adjustment.

V. ADMINISTRATION AND FINANCING

The Salvation Army

The Community Living Project is one of several projects sponsored and operated by the Salvation Army's Bureau of Social Services. While the Salvation Army plays a leading role in providing residential services of varying kinds in San Diego, the Community Living Project is their first venture into residential training services for mentally retarded persons. In the planning and operation of the project, they have relied heavily on the collaborative efforts of many community agencies.

The Salvation Army has an elaborate administration of regional and divisional offices that operate according to strict protocol. The Central Advisory Board acts upon what is recommended by the project's Advisory Committee. A direct link is maintained with the project through the appointment of three Central Advisory Board volunteers to the project Advisory Committee. In addition, the Director of the Department of Social Services also sits on the project's Advisory Committee. These representatives interpret its policy to the committee, thus insuring conformity of the project's planning with Salvation Army policy.

The Salvation Army plays a major role in determining whether or not program ideas are financially and operationally feasible, and if they are, it becomes actively involved in obtaining funding for the project.

The Advisory Committee

The Advisory Committee, set up especially for the operation of the Community Living Project, is a sophisticated committee composed of Salvation Army staff and volunteers, project staff and parents, and staff members of several community agencies.

Initially, and throughout the planning year, this committee was called the Steering Committee. It was composed of community agency representatives led by Betty Arnold, formerly Assistant Director, Bureau of Social Services, Salvation Army (the project's founder; see p. 10. When the project moved into the operating stage, a chairman (someone other than Salvation Army personnel) was appointed, and Salvation Army personnel and project staff were added. The first Advisory Committee Chairman was a staff member of the San Diego County Association for Retarded Citizens. The Salvation Army personnel added included Brigadier Yardley; G. Walter Coles, Bureau Director; and Mike and Patti Doyle, Resident Managers. One resident of the Community Living Project also sits on this committee; however, the committee meets during the day, thereby conflicting with the day program and the resident is not able to attend these meetings. (A list of participating agencies appears in Appendix B.)

Members of this committee attend monthly meetings in addition to working on subcommittees. All members are committed to the project, and some of them work 15 to 20 hours per month on a regular basis. It is this committee that determines the direction of the project by establishing policy based on recommendations from the three subcommittees: the Program Committee, the Finance Committee, and the Screening Committee.

The Program Committee includes six members of the Advisory Committee, and one resident. This committee has a broad range of responsibilities in providing consultation, and in coordinating resources for the training program. They formulate methods of carrying out program ideas, and aid the staff in implementing them. Some of the specific things the committee has worked on are: selection and coordination of educational courses in cooking, nutrition, first aid, and sex education; obtaining work placements; seeking information from related programs that might be applicable to this project; developing an informational brochure about the project; developing and refining evaluation forms for assessing the resident's progress in learning skills.

The Screening Committee, though no longer functioning, utilized the guidelines set by the project and the Public Housing Authority to select the original applicants for the apartments. They also maintained relationships with other community groups, and arbitrated with them about specific problems that arose concerning any resident of the apartments.

The Finance Committee has the monumental task of working with Salvation Army staff to seek out funding sources, write proposals, and develop budgets. This has been a time-consuming task. So far this committee has been instrumental in obtaining funds from the State Developmental Disabilities Council, United Ways, Convair Contrib Club, Country Friends, the Salvation Army, and the Regional Center. Through the efforts of this committee, the Salvation Army and others, some of the funding for the coming year is being obtained through Revenue Sharing.

Financing

The Community Living Project has an annual budget of about $52,000, (See Table 1) which reflects training and counseling costs. As mentioned before, tenants pay their own living expenses. Training costs amount to about $150 per month per resident, and funding sources for these costs are several. In the coming year, more than half the funding will derive from Social Rehabilitation Services, (i.e., the Department of Health will cover fifteen of the twenty-six residents). Seven residents will be funded through Revenue Sharing funds, and two by the Regional Center which vendorizes the project for $143 per resident per month. During the past year, the Salvation Army, Developmental Disabilities, United Way, and private foundations have also aided in meeting expenses. The major budget item--more than 80 percent, is for administration and personnel costs.

Residents receive income from Social Security, Veteran's Compensation, and employment. Typically, a resident's income is about $235 per month of which 25 percent is paid for rent and utilities. Average rent paid by residents for their city-leased housing apartments is between $40 and $50 per month for studios and one-bedroom apartments which would rent in the open market for about $130 per month. Residents budget their remaining income for basic needs such as food, clothing, transportation and entertainment.

While the project's first two years of funding has at times been precarious, the staff is looking forward by reason of the project's continuing success, to a more stable funding base in the coming year. With the collaborative and unified support of many community agencies, it is difficult to imagine, even as a remote possibility, anything less than solid funding for the future.

Table 1

Community Living Project Budget

Income:	1973-74	Proposed 1974-75
Revenue Sharing	$ - 0 -	$26,864.00
State Regional Center	2,990.00	3,600.00
Social Rehabilitation Services (Dept. of Health)	8,064.00	19,372.00
Developmental Disabilities	16,470.00	- 0 -
United Way	5,467.00	- 0 -
Private Foundations	5,800.00	- 0 -
Salvation Army Association	15,169.00	- 0 -
Client Fees	- 0 -	1,992.00
Total Cash Revenue:	$53,960.00	$51,828.00
Expense:		
Personnel & Administrative Consultation		
Project Director (half-time)	$ 6,800.00	$ 7,800.00
Social Worker	9,600.00	9,900.00
Residential Counselors II (2)	8,840.00	9,282.00
Residential Counselor I (1)	3,900.00	4,095.00
Clerical (one-third time)	500.00	1,600.00
Fringe Benefits (15%)	4,150.00	4,902.00
Consultation, Salvation Army Adm.	5,500.00	5,500.00
Total Personnel & Administrative Costs:	$39,290.00	$43,079.00
Housing		
Rent (two apartments, live-in counselors)	$ 3,120.00	$ 3,720.00*
Furniture Rental (tenant's apartments)	8,500.00	1,000.00
Insurance (Liability, fire, accident)	830.00	830.00
Utilities (Counselors' apartments)	240.00	360.00
Telephone	185.00	214.00
Maintenance and repair	25.00	25.00
Total Housing:	$12,900.00	$ 6,149.00

*Tenants now pay own furniture rental.

Expense:	1973-74	Proposed 1974-75
Office Expense		
Consumable supplies: office, training	$ 400.00	$ 600.00
Printing, publications, xeroxing	195.00	200.00
Postage	200.00	200.00
Total Office Expense:	$ 795.00	$ 1,000.00
Travel		
Local and conference staff travel	$ 900.00	$ 900.00
Other		
Consultation: Psychiatric for Clients or staff training	$ - 0 -	$ 100.00
Stipends to Clients: Incentive payments for non-paid clients	75.00	100.00
Miscellaneous Program Expense	- 0 -	500.00
GRAND TOTAL:	$53,960.00	$51,828.00*

Training cost per resident per month -- $ 150.00

Training cost per resident per year -- $2,000.00

*Training costs exclusive of tenants' room, board and expenses.

IV. OBSERVATIONS

After two years the Community Living Project has experienced success in training people to live independently, and their success can be traced to several conditions of the training community.

Program Structure

Several elements of the project's structure have contributed to its working well. The Advisory Committee, unique in its collaboration of a number of community agencies, is a sophisticated group that is strong and broad-based in directing the project--it provides a wealth of expertise and resources, and lends direction through the funding maze to obtain needed monies. Also unique, is the relationship of the project to the housing authority which is advantageous both to the administration and the residents in providing good housing that is financially feasible. At the same time, the apartment community builds in the opportunity for independent living in separate apartments. A bonus is that graduates are able to transfer to similar housing in a later, more independent phase of their training.

Staff

Both the staff and the planners are dedicated to the project and contribute their efforts in a generous manner. In fact, caution might be raised to the staff about the need for them to set more limits on the times when they are available to the residents.

Of perhaps even more importance then the time that the staff and Advisory Committee dedicate, is their insight into the means by which independence is learned. They admit that there is no magic formula, and yet they possess notable insight about growth. In their balancing of freedom and support, they continually evaluate the staff function and relationship to tenants. This is especially evident in their concern about how much program they should impose, and in their offering of alternatives when it would be simpler to set up either/or situations in the training. Risk-taking and flexibility characterize the nature of their relationships to tenants, and at times they are criticized for too little control, while at other times they are criticized for too much control. But judging by the response and progress of the tenants themselves, the balance is a good one.

Sense of Community

An unplanned for by-product of the program is the sense of community that has developed. In day-to-day activities and in group meetings,

friendship and trustful sharing indicate a supportive network that in itself spawns growth. The commonality of the tenant's situations and experiences promotes a level of sharing that probably could not exist in another type of community. Residents provide for each other measures of achievement, comparison, and competition that are near and attainable, and probably more useful in spawning growth than the more external standards of normality that can be sources of frustration to retarded adults with potential that is better defined in their own terms. The "community" provides an important ingredient in their development of self-esteem—pride and confidence in themselves as individuals.

Meeting Objectives

Finally, the project has met most of its own objectives, and this is in the evaluation of community programs, one of the best measures of success. Goals established at the beginning of the project were:

(1) To provide for mentally retarded adults with potential for independent functioning, a place where they could learn and practice the necessary living skills and move to more independent arrangements within six months to two years, thereby providing an alternative to lifelong family or institutional care.

(2) To demonstrate the strength of a collaborative inter-agency approach to the project.

(3) To stimulate the establishment of other such projects.

The first objective has been met in the graduation of four residents within a two-year period. Graduates are living independently with only weekly visits from staff, and seem to be living well, though the trial period has been short.

In meeting the second objective, the project has, as mentioned before, certainly drawn upon the support and commitment of all agencies involved. Advisory Committee members maintain that the work could not have been done without this collaboration.

It is likely that the third objective of stimulating the establishment of other similar projects has also been met, although this is more difficult to ascertain. Information has been given to many, and a couple of programs have been subsequently initiated that contain at least some of the program elements of the Community Living Project.

Certainly the experimental model has proven successful as a spawning ground for developing the confidence and skill of retarded adults who presently participate in the program, as well as for the graduates, and therefore most probably for future residents as well.

Appendix A

Excerpts from "Expectations of Tenants Participating in the Community Living Project". Before residents are accepted into the program they must explicitly agree to these "expectations".

"WHILE YOU ARE LIVING IN A COMMUNITY LIVING PROJECT APARTMENT, YOU WILL BE EXPECTED TO:

1. Take any medicine your doctor has prescribed regularly.

2. Pay your rent regularly, in the amount determined by the City Housing representative, in advance once a month: Pay utility bills (and phone, if you have one) promptly: pay any costs for which you are responsible; pay for repair of any damage to property caused by you.

3. Do your own shopping and meal preparation, with assistance of manager if needed.

4. Take comple care of your own apartment; help with care of areas that you share with other residents.

5. Keep yourself, your clothing, your bed linen and towels clean and neat.

6. Be occupied during the day with a job, school, a workshop or activities program, volunteer work or other activities that will help you become more independent.

7. Respect the rights, privacy, and property of your fellow tenants and nearby neighbors.

8. If you receive public assistance, let your eligibility worker know promptly of any change in your income or address, so that your checks can be mailed to you on time and in the amount you are entitled to receive.

9. Report any injuries or accidents to the manager immediately.

10. Attend the weekly tenant meeting -- it is your meeting.

11. Abide by the rules which apply to the apartment building in which you live.

12. If you need help in meeting any of these expectations -- ask for it. The manager is there to help you.

Appendix B

Participating Agencies:

California State Department of Vocational Rehabilitation

California State Department of Health, Community Services Section

Convair Con-trib Club

Country Friends

Grossmont Work Training Center

Home of Guiding Hands

PHASE (Protective Health and Safety Education)

Rohr Will-Share Club

San Diego County Association for the Retarded

San Diego County Department of Public Welfare

San Diego Regional Center for the Retarded

Security Realty (Representing the San Diego City Housing Authority)

United Way of San Diego County

F.

LORI KNAPP HOME

A rural community home for eight
moderately and severely retarded children

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The Proprietary Home Within the State Plan

I. INTRODUCTION

In developing a community-based system of services for the retarded, it quickly became obvious that many mildly and moderately retarded people could function in the community. More often than not, they have demonstrated their ability to handle the challenges of community life; indeed even to develop new skills. However, what about retarded people who are severely impaired or who cannot get around and need constant care? Is it possible to provide residential care in the community which is equal to or better than the care they could receive in institutions? The Lori Knapp Home, a residence for eight moderately and severely retarded children, located in the rural town of Prairie du Chien in southwestern Wisconsin, is an indication that it is possible.

The children are blossoming from the effects of a home and family life after living in a state institution for several years. Across town is a group home for adults which is another Knapp home. These adults, along with members of the Knapp family and families of the houseparents, form an extended family for the children--giving them a sense of security that greatly enhances their growth.

The philosophy underlying daily life at Lori Knapp Home is to give the children a homelife that is like that of any other normal family. The family here is a large one of eight children. As in any large family, older children help the younger children. Only here aiding each other means helping your brother get off and on his chair when you can walk and he can't, or feeding your sister who is the same age but can't feed herself yet. It means too that the only chores you might be able to do are those you can do from a sitting position. While these physical differences might be different from the average home, the working of the family group or system is the same as any other cooperative system in which you do the things you are best at, compensating for the deficiencies of your brother, while he compensates for you. There is a pervasive feeling of the home that it is a close-knit family that works well together.

The Lori Knapp Home is a part of the State of Wisconsin's plan for deinstitutionalization (or Community Living Systems Program as it is called), but more, it is the fruition of one man's dream to bring his daughter home from the institution to her own community. The founder, Donald Knapp, wanted to create a home where his own daughter Lori, who was then in an institution, could live. With the aid of the State Department of Mental Retardation, the State Association for Retarded Citizens, and the Central Wisconsin Colony and Training Center, he started the home in 1972. They decided on a home for eight, chose the children, and then built the house especially for the children with their

needs in mind. For two years now this "new family" has been living together working out ways to get their physical and emotional needs met. While they are still working on some things, like finding the time in their busy schedule to get all the physical therapy done, they have grown to care about each other and to communicate their caring to each other, a notable accomplishment for any family.

The home is also a unique demonstration of a state plan for community living. The State Bureau of Mental Retardation focuses on proprietary group homes as primary models for relocating institutional residents to their own communities. Presently there are 54 such homes in Wisconsin with plans to develop 50 more within the coming year. The plan is workable because of the active role of the state institutions in providing community consultation, staff training and supervision.

II. DEVELOPMENT OF THE HOME

Beginnings

Lori Knapp Home is named for one of its residents, Lori Knapp, and indeed came into existence because Lori needed a home in her own community that would fit her needs. Seven other children share the home with Lori, and it is no less their home than hers, but Lori did provide the inspiration to develop it.

Lori was born in 1959 with Cerebral Palsy, and later was diagnosed as severely retarded. For the first five years of her life, Lori was more dependent on the care of her parents, Don and Bette Knapp, than most infants: all foods had to be pureed and slowly fed to her in a process that took nearly two hours a feeding; she had to be given physical and occupational (self-help) therapy daily; she had bronchial difficulties, digestive and intestinal difficulties, and often had trouble sleeping. As she grew, she was unable to walk or crawl and had to be lifted from place to place, and required a special chair in order for her to sit at all.

Though Don and Bette loved her, and at times were nurtured themselves through their caring, they became physically and emotionally exhausted--both from their care of Lori, and the limitations her care put on their own lives. In 1964, after wrestling long with the decision to place Lori out of the home, the Knapps admitted her to Central Wisconsin Colony, a modern institution two hours drive from their home. As Don Knapp looks back on this time, he reflects: "Respite care would have made the difference between going and not going to the institution."

Lori received care that was adequate according to institutional standards of care, but it did not help her develop her capacities fully. After five years at the age of ten, she was transferred to Northern Wisconsin Colony to a special Cerebral Palsy Program. The program was an excellent one where she received self-help training through the aid of skilled staff and innovative techniques and equipment. Lori made slow, though observable progress in communicating (in her own subtle ways), in responding to communication, and in control of her muscles. Unfortunately the program was short-lived, and soon collapsed because of staffing and funding difficulties. To the Knapps this was heartbreaking news. It meant that Lori was miles away from home, and without a program suited to her special needs. It was then, in 1969, that they began to seriously explore how they could provide for Lori in their own community.

Don Knapp, a successful furniture dealer, began to talk with friends he had worked with for several years on committees and boards dealing with Cerebral Palsy and Mental Retardation. He knew that the community schools had the potential to provide educational support through their county Personal Development Center that had been under way for five years, and through the TMR class at the public school. Both these programs would

probably need additional staff if they were to work with more children, and that seemed easily solved. He thought and talked about household help for Lori in their own home, and about expanding the day program at the Personal Development Center, but the most attractive idea he came upon was that of a group home--a home that would provide 24 hour care, and would give Lori the opportunity to live with other children like herself, in a family atmosphere.

In early 1972 Knapp was encouraged by the Chief of the State Board of Mental Retardation to go ahead with the development of a group home. With a handshake and verbal support, Knapp agreed to sit down right then to work out a budget for the home. They developed a budget based on a home for eight children, the smallest number of children the home could have and still be financially feasible, given the monthly support paid for the children by the state at the time, and the largest number possible for group home licensing. They were able to work the budget out in fair detail, and although it appeared there would be a small monthly loss, Knapp was convinced that the home was workable. Then they sketched a plan for the home and its program to submit to the Central Wisconsin Colony where they hoped to select the children. The plan was both exciting and awesome to Knapp--exciting because it was the fruition of a long-time dream to bring Lori home, and awesome because it would be the first group home in the state under the new Community Living Systems Program, which meant many unknowns about how it would work.

Resident Selection

Unlike the more usual steps in developing a group home where the home is selected first, the children were the first to be selected for the Lori Knapp Home. Knapp requested four boys and four girls be assigned to the new home--four who could walk without the aid of crutches or wheelchairs and four who needed aid in getting around. The thought was that it would be better for each child to be paired with one other person like themself, but that the disabilities of the children should be mixed.

The Central Wisconsin Colony responded to the selection description by drawing up a list of 16 potential candidates for placement in the home--children who fit the criteria and were able to live in the community. The selection process was long and difficult. The Knapps wanted to take all the children, but that was not possible. Moreover the motivations of the Knapps and the Colony were slightly different. The Knapps were looking for children that would make a good family, and for children to get along with Lori. Some Colony staff, on the other hand, were looking for removal of hard to place children or of children they liked and wanted to have a home. In retrospect the selection could have been handled more efficiently, taking less time, and with fewer personal feelings involved. Nonetheless, the children were finally chosen.

The children were four to fifteen years old when selected. They are moderately and severely retarded, and four of the eight have severe physical handicaps. Two of the boys and two of the girls are confined to wheelchairs or positioning chairs, although the boys are able to occasionally crawl or use crutches. The other four children can walk and run but they have speech, coordination or visual (perception) difficulties. Their mental and physical disabilities are the result of a variety of conditions: Down's Syndrome, Cerebral Palsy, Hydrocephalus, Spina bifida, Porencephaly.

Groundwork for the Building

Once the children were selected, Knapp proceeded with plans for the building. His idea was to locate an appropriate site in a nice part of town and have a modular home built to specification. However, before he got very far with this plan, he was distracted for three months when he pursued an offer of a large hospital. This did not work out, so he returned to the original plan.

He located a site on the west side of town across the road from the Mississippi River. The site did not have to be re-zoned for the group home, but a use permit involving a public hearing was required. For several weeks prior to the public hearing there was newspaper publicity about the plans for the home, and on the night of the hearing Knapp discovered there had been a telephone campaign against the home. It was initiated by a neighbor who in the process of selling his land adjacent to the site, had been told by the realtor that the land had not sold because a home for the mentally retarded was being built next door. Telephone complaints were also made by a large Wisconsin newspaper and a TV station. However, there was a larger turnout of people in favor of the home, and the use permit was granted with little discussion.

Obtaining the Building

Knapp needed $50,000 to start the home, and in order to finance it he drew from his personal resources. Through individual contacts by Knapp and his attorney with the bank officers, he was able to obtain a 90 percent loan for the land, building, and furnishings. Operating costs were obtained through a veteran's loan. To make up the small difference remaining, Knapp also borrowed on insurance policies. Later he found that his budget worked out very nearly to the penny.

The House

The home is a two level ranchstyle house specially built by a local construction firm that designs modular units. It is a contemporary, pleasing style with ramps for both front and back entrances for wheelchairs. In the corner of the front yeard stands a small hexagonal summer-house of stone which was on the property previously.

Upstairs on the main floor are the living room, kitchen, dining room, five bedrooms and two and one-half baths. Four of the bedrooms are occupied by the children--two children in each, and divided in such a way that there is a boys and girls wing on either end of the house. The master bedroom and half bath are quarters for the houseparents. The decor creates a cheerful, comfortable, and warm atmosphere and the carpets and fabrics are practical and durable. The centers of activity are the living room where the children watch television and the dining room where twice a day the large family eats together around the long dining table. Mealtime is an enjoyable time. Children cooperate in setting the table; everyone convenes at the table with keen anticipation about the meal, and in chorus say one of several prayers they have learned by heart. The prayer is a delightful and uplifting sound.

Downstairs is a large basement divided into den and recreation areas, that is a favorite place of the children. All year round they enjoy the spaciousness, but it is especially useful during hot weather, and seasonal rains and snows. Often they play ping-pong and pool in the recreation area, and play the piano or sing along to records in the den. Future plans for the space include a workbench for woodworking projects. Two bathrooms, a laundry room with non-commercial washer and dryer, and a storage room complete the downstairs.

Special features of the house make it very nearly ideal in meeting the children's needs. Wide hallways and doors allow wheelchairs easy passage, in fact so much so that speeding wheelchairs keep you alert in the hallways! (One of the boys has won several Special Olympics ribbons for wheelchair racing.) The bathrooms are unusual: one has a chest-high bathtub, and a low, child-size toilet, while the other has a shower with an adjustable spray hose that is designed for use with a plastic chair that rolls right into it. Between levels is an electric chair that all of the children ride at times, although it is only actually necessary for some of them. The only inadequacies of the house seem to be insufficient space for the houseparents, and laundry equipment that is too small for such a large family. (Washing is larger than a normal family since several of the children wet their beds.)

Outdoors is a large front and back yard, shaded with a number of trees. In the back is an ample wooden patio with an umbrella table where the children sometimes sit and draw or play games, and a basketball court used by the older boys.

Community Response to the Home

The Prairie du Chien community has responded very favorably to the home. Dennis Harkins, Central Colony's social worker for the home, says:

> The Knapp Home has not been hidden behind the tall reeds of the Mississippi River. The home and its residents have been quite visible and have enjoyed widespread community acceptance and support.

The Prairie du Chien "Courier-Press" has been extremely helpful in providing very favorable publicity for the home in occasional feature articles. In an article shortly after the home had opened, the paper very tactfully discouraged local residents from visiting the home without warning, helping us with what had become a very irritating situation. (Unannounced visitors were coming so often it had seriously disrupted the home.)

The community as a whole has also welcomed the home's residents in daily contact in stores, parks and various community activities and social events. There has been no significant opposition to the home since its inception; to the contrary, Prairie du Chien seems to be very proud of the Lori Knapp Home.

III. PROGRAM

Philosophy

The atmosphere of Lori Knapp Home is one of a caring and cooperative family. This atmosphere is as much a result of a motivating philosophy, as it is the result of spontaneous outgrowths of family relationships and values.

The motivating philosophy is the principle of normalization: "To provide as near a normal homelife as possible." Founders and staff interpret this to mean providing not only the physical home and supporting community, but a homelife that includes a family. To this end, care has been taken to create a normal family atmosphere. The home is physically as normal as possible, while still meeting the special needs of the children. Staff are chosen for their ability to assume a parenting role. Activities are as normal as possible. The children were even chosen with the thought in mind of creating a good family.

The family atmosphere is the spontaneous outgrowth of the relationships that have developed between people both inside and outside the home. Although the original expectation was that the children and the houseparents would form a family unit, more has occurred. The immediate family has extended to include the proprietors, their son and his family, the houseparents' and relief houseparent's families, and the adults at the nearby Knapp Adult Home. These relationships have grown spontaneously through repeated encounters with one another and are the result of the genuine interest and caring between the people. Mutually they meet each others' needs, through communicating their caring in innumerable small ways--in visiting, in shopping together, in having dinner together, in giving gifts--and everyone seems to have grown, though the focus is on the growth and change of the children who have all blossomed socially in their secure environment.

Cooperation is a dominant theme in the family, much like other large families. However, the manner in which they cooperate with each other is often different from the usual cooperation of siblings. While the children, like all children, are learning to cooperate in playing together, they also help each other physically. Two of the older boys often help to lift the four children who have limited or no movement of their limbs. Commonly you see Danny or Larry move without instruction to aid in transferring other children from their wheelchairs or positioning chairs to dining chairs, or from floor to sofa, or from bathroom floor to the toilet. The aid relieves the staff of part of their work, but more importantly, it gives the boys a feeling of contributing.

Staff: Role and Training

The home is staffed by five people: two primary houseparents, a relief houseparent, a part-time aide, and a cook. The primary houseparents are a young, but mature couple who formerly worked at Central Wisconsin Colony. They answered a newspaper ad to obtain the position which they were especially interested in since they could utilize their Colony work experience in a home situation that was located near their hometown. The woman works in the home five days a week, while her husband holds a full-time job elsewhere. She has the primary responsibility for managing the home and works within a budget outlined by Knapp. She prepares work schedules, arranges the children's visits to the colony for things such as brace adjustments and other services that are not obtainable in the community, does laundry, housecleaning, and part of the grocery shopping. For a large family of eight children these are ominous and time-consuming tasks that require competence, enthusiasm, and energy.

The relief houseparent, a nurse who is a long-time friend of the Knapps, works in the home two days a week, staying overnight one or two nights a week. She aids with all the tasks of the houseparent, and has worked in the home since its beginning two years ago. She shares her time with the adult home where she also relieves the houseparents. Her position is a difficult one because of the part-time nature of the work, and she does well in compensating for this.

The part-time aide is the 18 year old daughter of the relief houseparent. She works several hours a day, according to a flexible schedule that fills gaps in scheduling for the house. She too aides with the care of the children and the household responsibility, but her primary responsibility is that of the physical therapy. The colony provided a week long intensive training for her to learn this work. She has natural skill for the therapy, but because of the busy schedule of the household, the therapy does not get done to the satisfaction of the Colony staff. This is viewed as a rather serious problem since the physical therapy is of great importance in helping the children to maintain and increase use of their impaired muscles.

The cook, who works three hours each evening, does the shopping, food preparation, and meal cleanup. This seems to be an important job for someone other than the houseparents to assume in order to relieve them for working with the children. Breakfast and lunches are prepared by the houseparents.

The staff view their jobs much like that of a parent. In fact they have been selected for their ability to be warm, loving parents. They relate to the children just as they would to their own, and discipline with a firm, but loving hand. Occasional necessary punishments are usually things like being kept home from a desired activity, or being sent to a bedroom, rather than spankings, and even this is done with caring. In fact, the general manner of relating to the children in any

matter is notably characterized by kindness, patience, and affection. It is also apparent that the staff is enjoying themselves at the same time, for nearly all the original staff has remained since the beginning of the home. (One part-time aide quit for personal reasons, and two cooks have left.)

A probable reason for the success of the staff in caring for the children is the training they have received from Central Wisconsin Colony. Prior to being hired, the houseparents attended staffings about the children and orientation sessions at the Colony to acquaint them with the children and their needs. Once the home was opened, the home received weekly visits for two to three months from the social worker and frequent visits from a physical therapist, occupational therapist, and speech therapist from the Colony. The visits have tapered off, but the home continues to receive supervision from the Colony social worker. According to the Colony, this home has received more training time than any other group home, and judging from the success of the home and the staff, the time has been valuably spent.

A Typical Day

Typically a day in the home begins when the children wakeup at 6:30 a.m. Beds are made, and the children are washed, dressed and ready for breakfast by 8:00 a.m. For a normal family school mornings are often a rush, and for this family it is even more rushed--at least for the houseparents. Since only two of the children are able to make beds and dress themselves without assistance, the houseparents must scurry among the other six to assist them, whether it be with step-by-step instructions, or with extensive or total care that requires lifting and carrying the children. After breakfast, six children are picked up at the front door for school, and a few minutes later the busvan arrives to take the other two to the Personal Development Center.

While the children are in school, the houseparents do the laundry, housecleaning, lunch preparation (for the two children who come home by lunch time), shopping, and keep doctor, dentist, and Colony appointments. All of the children are home by 2:30 and often have a half an hour nap before playing and physical therapy. Dinner, prepared by the cook, is between 5:00 and 6:30, which leaves two more hours before bedtime for TV, recreation and baths. Bathing is a long process requiring continual supervision or full assistance, so baths are usually staggered--boys one night, and girls the next. Sprinkled with all the unexpected things such as last minute appointments, or special recreational events, this adds up to a very busy schedule.

Daytime Program

During the day six of the children attend the trainable class in the public school while two participate in the County's Personal

Development Center. The admission of the children to the TMR class has doubled the size of the class; however, the school district has cooperatively adjusted by adding an additional teacher. This addition was accomplished through the efforts of the Colony staff and Don Knapp despite the short notice the school was given. Colony staff has continued for two years to provide consultation for the teachers who had little experience in working with non-ambulatory children. While the progress of the children is slow, they have each made some academic progress. The least amount of progress is notable though since it is the first time most of the children have attended a public school. Both their academic and social adjustments to the new situation have been at times difficult, but now school is an enjoyable activity. As most children they even create school-type projects for themselves to do at home, and proudly display their drawings or writing.

Two of the children have been welcomed into a county-operated Personal Development Center for handicapped children. The program had not previously included children with cerebral palsy, and they have had to adapt teaching methods to fit the needs of the new children. Colony staff has also provided these teachers with instruction and consultation in physical and occupational therapy, and the teachers have responded cooperatively.

During the summer the children receive home teaching to maintain their skills in reading, motor, social, and personal hygiene at a level they had attained during the school year. The program, for former Colony children, is funded by the U. S. Office of Education.

Recreation

Fun is highly valued at the Lori Knapp Home. Don Knapp and the houseparents spend a goodly amount of energy, and what is often their personal time, to plan activities for the children. Picnics, walks, swimming, trips to Madison, parties, and dances are among their favorites. The adult home has a large indoor heated swimming pool which Don Knapp makes available to all handicapped children in the community. The children at Lori Knapp Home make frequent use of it which keeps them in touch with the adults there. Parties and barbecues are often planned at the adult home. However, a major event of the year is the Special Olympics.

The basement recreation area was the training site for the Special Olympics, and several of the children won awards in the meet this year. Their badges and ribbons are proudly displayed in the frontroom.

Badger Camp, another highlight of the year, is a summer camp for severely and moderately retarded which serves more than 400 people every summer. Parents, teachers, and others (among them, Don Knapp who is presently on the camps' Board of Directors) started the camp through the

local Association for Retarded Children in 1966. Staff who are working or interested in working with handicapped children are recruited from several states. Music, swimming, field trips, arts and crafts, and camping are but a few of the camp's activities. The camp is a source of conversation among the children throughout the year, and their excitement is barely contained as time approaches for their week at camp. Badger camp T-shirts are worn at every opportunity, and of course promote enthusiastic conversation about camp.

Recreation is somewhat restricted by the lack of transportation. The home does not own a van or bus. Consequently, while special activities are frequent when transportation can be arranged, after-school activities are limited to walks, playing in the basement or the yard, and occasional swimming at the adult home.

IV. RESIDENTS

Central Wisconsin Colony has custody of the eight children in the Lori Knapp Home, and oversees their health, development, and education. The Colony social worker assigned to the home, visits once a month, and maintains close communication with the houseparents and schools about the needs and progress of each child.

From the profiles that follow,* it is clear that while both the home and the children have undergone the adjustments of newness within the past two years, the children have been positively affected by their living in the home. Though the children are different, what is common to them all is that they have all changed for the better as a result of their new, secure family.

Ann

Ann, age 13, is attractive with short blond hair and glasses. Generally she is very enthusiastic, especially about music, although she is at times pensive. She was admitted to Central Wisconsin Colony when she was five years old because her aggressive, hyperactive behavior was too difficult for her parents to cope with. She had an abnormal birth, and it was discovered that she had hydrocephalous which was treated by operating to insert a shunt. She appears to be moderately to severely retarded, but has no physical impairments other than a perceptual problem that often causes her to loose her balance. Before coming to the home, she had been placed in two different foster homes for short periods of time, but neither of these was workable because she needed constant supervision.

Ann was extremely enthusiastic about the Lori Knapp Home and settled in very comfortably and well. She has responded to the kind firmness of her houseparents, especially to their attempts to help her be more assertive about her wants. She used to simply agree with whatever was said or offered to her.

She is an extremely cooperative, good-natured child who tends to depend excessively on others (a trait associated with long-term institutional living). She has improved in this respect over the past two years, becoming more assertive and self-confident and less withdrawn: making autistic-like patterns with her hands is no longer a preoccupation as it once was. Her social and self-care skills are somewhat refined; she is neat while she used to be sloppy and now takes pride in caring for herself. Ann's behavior has presented few problems over

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*Thanks is given to Dennis Harkins, Colony Social Worker for his reports which provide the basis for these profiles.

the year, although while she rarely does it now, she often whined and begged for things she wanted.

Ann attends the Prairie du Chien trainable class at the public school and has become one of their better students. Initially she had been behind the academic level she had achieved at the Colony, but she has gradually regained and surpassed that level now.

Ann's parents have not been in contact with her over the past year, but recently when they called the Colony about a technical question, they expressed interest in her progress and said they would like to visit. They have been encouraged to become more involved in Amy's life.

Danny

Danny is a handsome young man of 17 with dark hair, a lightly freckled nose, a sturdy build, and a charming, enthusiastic manner. Danny was admitted to the Colony when he was one year old, but was soon placed in a foster home for six years. His foster parents moved out of the state, and Danny returned to the Colony. It seems that he is moderately to severely retarded, a result of Down's Syndrome. Physically he is very capable inspite of a minor coordination problem.

Danny is one of the oldest, most responsible children in the home, and an extremely sensitive, emotional and affectionate young man. He does get depressed on occasion, but usually for good reason. (He was very sad over being the only one not to win a ribbon at Special Olympics.) He has at times been mildly depressed following the visit of the natural parents of one of his foster siblings. Usually he recovers rather quickly; however, sometimes through the use of his imagination (for example, he created an upcoming visit by his parents following the visit by Larry's parents). His occasional moodiness is a very human problem and there has been no attempt to modify it.

Overall, Danny is very happy in the Lori Knapp home, and in fact contributes to the family by often helping with the younger, more dependent children. He gets quite enthusiastic over whatever he is doing and at times must be calmed down somewhat. He is a capable, helpful young man, and may have the potential to some day work in the community, if the proper job and supervision could be found. He is perhaps the most academic and artistically oriented of the group and does very well at school (Prairie du Chien trainable).

Danny's father occasionally calls the Colony to discuss Danny's progress and receives periodic reports. His mother has in the past been hesitant to visit him.

Dianna

Dianna is a vivacious, round-faced young lady of 15, whose pigtails and impish grin seem to immediately give away her mischievous streak. She too is a child with Down's Syndrome and moderate to severe retardation, and physically she has only slightly deficient coordination. She was admitted to the Colony directly from the hospital after birth. She left the Colony for three foster home placements which were not successful, because of her aggressive behavior.

Dianna has presented the home with its greatest behavior problem. She can be extremely stubborn, hostile, uncooperative and destructive. During the first few months of placement, her behavior was almost completely unmanageable by anyone but the houseparents. Her social and group play skills were almost non-existent, she was extremely possessive and demanding, and she threw frequent, violent temper tantrums. There was serious discussion of returning her permanently to Central Colony.

However, the houseparents have consistently handled her with firmness, first asking her to change her behavior, then physically removing her from the situation if she does not. Through extreme patience and understanding her beh vior improved and the home weathered the storm. Knapp, the caretakers, her teachers and Colony staff communicated very well to one another to insure a consistent, firm approach to her behavior. Dianna's competence in domestic areas and desire to be of help are used to keep her busy and to provide her some of the individual attention she desires. Gradually her behavior has become markedly less self-centered, less demanding and is now for the most part quite manageable. She now rarely has tantrums, except if being handled by strangers.

Dianna is an extremely capable child relative to her disability. She is very helpful both at home and at school in the Prairie du Chien trainable class. She is now for the most part a pleasant, affectionate girl who shows occasional signs of becoming a young lady. The "tiger" is not too far from the surface, however, and many people still tread quite softly around Dianna.

She appears to have excellent potential to learn to care for herself and to eventually function in a sheltered workshop type setting.

Karla

Karla is an exceptionally cute little girl of six years old with dark curly hair, big blue eyes, and a captivating smile. Her parents gave her up for adoption at birth, and she was placed in a foster home. After a year her foster parents discovered the severity of her physical problems and admitted her to Central Colony where she remained until her placement in Lori Knapp Home nearly two years ago.

She is rather severely handicapped due to a rare condition called porencephaly--one side of her brain did not develop. She has a good deal of difficulty holding up her head, and very limited use of her lower limbs. She uses a positioning chair to obtain a sitting position, and is able to feed herself quite well in it--a remarkable achievement. In fact she makes encouraging spurts of unexpected progress. She is slowly learning to form words and communicate what she wants with the aid of a communication board prepared by her speech therapist--a book of labeled photographs of articles in her home that is propped on a slanted wooden stand on the tray of her chair.

While Karla requires more individual attention than almost anyone in the home, she is a delightful addition. She is cheerful, cooperative, affectionate, and usually, except for occasional stubborness and laziness, determined to succeed in everything she tries. Unquestionably the staff has deep affection for her, and she seems to have become increasingly happier, has improved her eating skills, and is now potty trained. However, the Colony staff has not been pleased with the fact that her physical therapy has often been neglected, particularly during the first year. The therapy is necessary if she is to avoid having corrective hip surgery.

During the day Karla attends the Personal Development Center which is not as stimulating for her as it should be in meeting her special needs, although the staff has done a good job adapting to her. It is hoped that soon she will be able to attend a multiply-handicapped classroom in the public school.

Kevin

Kevin is a handsome young man of 17 (though he seems younger), whose dark-rimmed glasses and shy grin give him a studious appearance. He is known for his sociability, his memorization of Johnny Cash records, and his slowness! His development had been normal until four months old when he had a head injury, followed by brain surgery. Now he is confined to a wheelchair most of the time, although he has developed a unique style of crawling that enables him to scoot along the floor. Intellectually he seems to be moderately retarded, although some of his disability is probably associated with his slowness and laziness.

Kevin's continual singing is a sign of his happiness at Lori Knapp Home. He gets along well with his roommate, Steve, and with everyone else who comes to the home. His abilities to care for himself and feed himself are fairly good, although he gets lazy about personal hygiene and control of his bladder and bowels. Progress in these areas is slow, as is nearly everything with Kevin--he is extremely slow moving. Several methods have been tried to get Kevin to accelerate his actions. Presently staff is trying a consistent program of ignoring the slowness since it is thought that frequent comments and jokes about the slow behavior are rewarding.

Dennis Harkins, the Colony social worker commented on Kevin's attitude and progress in the home:

> In general, I beleive Kevin is a classic example of institutionalization. Kevin has little sense of responsibility for his own care and would be quite pleased to be totally reliant on others. This lifelong attitude will not easily disappear, but a number of inroads have been made in changing it over the past two years. Kevin is basically a rather sensitive young man and the home has been helping him to understand that he can be helpful to other people by being more self-reliant.

During the day Kevin enjoys his work in the trainable class at school, and is working up to his capabilities. He will do well in the future in a semi-sheltered work situation in the community, and with continued training can learn to care for his own physical needs.

Steve

Steve, age 10, is a cute redhead with freckles, who is a champion wheelchair racer. He is quite talkative--socially charming with his enthusiastic telling of amusing stories and consequently is very likable. He was born with hydrocephalus, and Spina bifida which have left him moderately retarded and without the use of his legs, although he is learning how to wear braces and walk with crutches. At a young age he was admitted to an institution in Illinois, and was transferred to Central Wisconsin Colony at age five.

Prior to coming to the Lori Knapp Home, he lived for a year in a foster home where he became such a severe behavior problem the foster parents requested he be removed from the home. He was underweight, anxious, tense, insecure, self-depracatory, and at times hostile. He had refused to take care of his diapering (he wears special diapers since he has very limited control of his bladder and bowels), and had been self-abusive in creating sores on his bifida and toes.

Steve's placement in the Lori Knapp Home has been an overwhelming success. He has gained weight (in fact almost too much), and is relaxed, happy and secure in his new home. He is well liked and plays well with the older children, and has taken a special interest in helping with Lori and Karla--sometimes he even feeds them. Also, while in the past his negative attitude toward his braces has been a severe problem in learning to use them, he is now walking a few hours a day with them on. The staff has helped him in learning to view his braces with pride, something which no one else had been able to do before now. Still Steve needs a good amount of social reinforcement for his positive behavior from those around him and it seems that he is now getting what he needs.

He does well in the Prairie du Chien trainable class, being possibly the brightest one in the class.

Larry

Larry is an athletic, gangly youth of 17, who is shy and good-looking and very sociable. You might even describe his appearance as all-American and wholesome. He was born a Down's syndrome child, is severely to moderately retarded and has slightly deficient coordination. He was admitted to Northern Wisconsin Colony at eight months old, and transferred to Central Colony at four years old. After a year he was placed in a foster home where he lived for eight years until his foster parents left the state.

Since Larry has a history of being well-adjusted, relatively happy, and cooperative, it is more difficult to describe the effects of Lori Knapp Home in his life. He continues to be cooperative, helping with the household chores and the younger children, and keeps busy playing most of the time. He develops games of his own with all sorts of objects, and plays endlessly, seeming very amused. It does seem though that he has begun to play more with the other children, while he used to play almost entirely alone. His personality has blossomed in the process; it is easier now to get to know him since he is expressing hi-self more openly. He likes school and does well there also.

Lori

Lori, 15, is a pretty young girl with pale blonde hair who smiles coyly with her head bent slightly downward and to the side. She is the Knapp's daughter, the one who provided inspiration for the development of the Lori Knapp Home. She spends weekends with her parents, and weekdays at the home.

She has a mixed type Cerebral Palsy that allows her little control of her head, trunk and arms. She, like her roommate Karla, uses a positioning chair (called a Hogg chair) to aide her in sitting. She has difficulty swallowing and using her mouth, so she needs assistance in eating. While she can pronounce only a few words, she has a well-developed system of communication that includes gestures, shaking her head yes and no, and eye movements. In fact she is a strong-willed young lady who often lets you know in no uncertain terms whether or not she is pleased: she laughs with glee, or cries loudly and pouts.

When the home opened, Lori seemed ungrateful for all the effort on her behalf, because she did not want to live in it! She cried loudly most of her first two nights there, keeping the houseparents awake. This was understandable though considering that she not only had to move from her parent's home where she had been living for the few months prior, but that she now had to share their attention with

seven other children. So, Knapps decided it was best to introduce her to the home gradually, and for a couple of weeks she spent days in the home and nights with her parents. She did learn to like the home and is now, according to her father, happier than she has ever been.

Lori does like the other children in the home, especially her roommate, Karla. They enjoy touching, laughing and babbling to each other, and you get the sense that beyond what you can see and hear is their own special and private communication. At times she is also moody because of her physical discomforts or her preference to be with her parents, or possibly because she compares her physical abilities with those of other children.

Her life in the home is a busy one. She gets about five hours of exclusive attention from the houseparents each day while she is assisted in eating, dressing, bathing, exercising. At mealtime she exercises her tongue, mouth and throat, and during physical exercise time, she strengthens her muscles and movements. One daily exercise is to stand in a "standing table" specially built for her by her father. The speech therapist from the Colony gives her speech training, and the home trainer from the Personal Development Center, which she attends a few hours each day, works with her on recognition of objects and symbols. In all of this she is doing well. She has made significant gains in controlling her head and body, and her health, which was poor, is now much improved, and Colony staff expect that she can greatly improve her eating. Above all, her increased alertness and awareness of her surroundings indicate her desire to experience herself in a fuller way.

V. ADMINISTRATION AND FUNDING

Administration

The Lori Knapp Home is one of two homes held in a private corporation with a non-profit motivation. The Board of Directors of the corporation, Knapp Homes, Inc. (includes the adult home), consists of Mr. and Mrs. Donald Knapp, and their son, Don Knapp, Jr.

The corporation is well-managed by Donald Knapp who is principally responsible for the administrative supervision of the home. He prepares and enforces the budget, while Family Care Services Division of Central Wisconsin Colony (state institution) administers the funds for the home.

Budget

The annual operating budget for the home is $33,600 or $350 per month per child (plus an additional $50 per month for clothing and personal allowances). Costs per child per year are $4,200. While these costs do not reflect the administrative and staff costs of Colony personnel who supervise and assist the home, or the costs of the Personal Development Center assumed by the state through a separate budget, the costs are significantly less than those of the Colony costs for care which amount to $2,000 per month per child (exclusive of the costs of the facility). The largest expenditure is for staff salaries, administration, and social services, which amount to approximately 30 percent of the budget. Rent, taxes and food are the other expenses that are significant budget items (see Table 1).

Funding Sources

Presently the home is supported by state grant-in-aid funds reimbursed through Family Care Services, 60 percent of which derives from state funds, and 40 percent from local funds. In 1975 this will change, however, to 100 percent state funding. The home is financially stable as long as it continues to be reimbursed at rates that are adjusted to meet rising costs. This is a source of concern to the home since this is the sole source of funding and the responsibility for funding is a continuing question (a current funding battle at the county and state level is whether the county of origin or the county of settlement should assume responsibility for the support of residents).

Table 1

Annual Operating Budget for 1973

Housing and Maintenance		
Rent (12% of cost)	$6,000	
Taxes (3% of cost)	1,500	
Liability Insurance	360	
Utilities	1,226	
Furniture depreciation (includes linens)	900	
Telephone	300	
Replacement of expendable household items	420	
		$10,706
Food		
Groceries		$ 6,600
Personnel		
Residential staff salaries	$7,800	
Fringe benefits	420	
Administration	1,200	
Social services	1,800	
		$11,220
Miscellaneous		
Contingency and emergency	$ 600	
Licenses and permits	60	
Legal and accounting fees	120	
		$ 780
Transportation		
Resident travel		$ 300
Total operating costs		$29,606
Initiating Costs		
(Mortgage insurance, lot preparation, legal fees, etc.)		$ 2,850
Grand Total*		$32,456

*1974 budget is $33,600: $350 per month per child; $4,200 per year per child. Does not include clothing and personal allowance of $50 per month per child.

VI. OBSERVATIONS

The Lori Knapp Home demonstrates that severely and moderately retarded children who are also seriously handicapped can live well in the community. That the children do live well is a testimonial to the internal quality of the home.

A major factor in the quality of the home is the attitude and relationship of the staff to the children. Staff expect normal responses and behavior from the children, and to elicit the responses, they have created a normalizing atmosphere, tempered with warmth and firmness. In a natural and spontaneous way, the staff has assumed the role of loving, caring parents, and relatives of the staff have joined them in providing a traditional extended family. The result is that the children are growing and maturing in unexpected measures in a secure environment that most of them have never before experienced. Dennis Harkins, Colony social worker comments on this:

> The creation of this new family is not of just sentimental importance. I believe it has a significant relationship to the growth in maturity, and the happiness and sense of security of eight children who have been in and out of various homes and institutions throughout their lives. It is no mean accomplishment that all of the eight children originally placed still remain; many had "flunked out" of previous foster homes and came into their present home with the same kind of physical, social and behavioral problems that had resulted in past reinstitutionalizations. Without the family-like concern and affection between staff and residents, it's doubtful that all of the present children would still be in the home.

Another factor in the home's quality is the availability and use of resources. Colony staff continue to provide invaluable assistance in supervising the staff of the home in their manner of relating to the children, and in physical, occupational and speech therapy. Without this assistance, it is doubtful that the staff would have the necessary support to provide not only the physical needs of the children, but the emotional needs as well. Here the staff has been given a supportive framework from which they can extend to meet the emotional needs of the children. Additionally, the community resources available--particularly the Personal Development Center, and the Prairie du Chien trainable class--provide the necessary academic component for providing the children with a well-rounded existence.

The Lori Knapp Home is indeed a quality home, but it is not without its problems and limitations. Though the selection of the children was based on some near-excellent criteria--financial feasibility, a good

family group, paired disabilities and compensating abilities--the composition and the size of the home sometimes pose management problems for the houseparents: eight is a large number of children for one home, especially since four of them are non-ambulatory and two require extensive or total care. This problem compounded results in a schedule that is often too busy to accomplish the necessary physical and occupational therapies. Although staff has become increasingly cognizant of the importance of the therapies, the Colony continues to express concern about this. It appears that a possible component of this problem exists in the staff's covert attitude that administering the therapies renders the home a mini-institution. However, the realistic approach to meeting the children's needs lies in finding the balance between providing a home environment that also includes the therapies.

A potential problem is that parents of a resident child own and operate the home. Houseparents could have difficulty implementing methods of handling a child which are contrary to the desires of parent-operators. The only evidence of this problem may exist in Lori's manipulations of her parents and houseparents in the early weeks of the home when she would refuse to cooperate until she saw her parents. However, this incident was easily resolved when the Knapps became clearly aware of the problem and told Lori she could no longer exert that kind of control. In fact, the Knapps have been very cooperative with the houseparents in this regard, but one can see that in other situations the parent-operator conflict of interest could pose a rather serious problem.

Finally, a significant problem, though not programmatic, is the lack of adequate transportation. Presently Knapp and the houseparents use personal automobiles to transport the children to school, community recreational activities, and medical appointments. This is a workable solution, though inadequate as it severely limits interaction with the community. Standard automobiles simply are not adequate for transporting several children with wheelchairs and crutches, and lifting the children, particularly the heavy ones, is strenuous. The home is in need of a busvan with space for eight children and their equipment, that is also equipped with a lift.

The Proprietary Home Within the State Plan

The Lori Knapp Home is representative of a unique state plan that utilizes proprietary homes as a primary model for Community Living Systems. Advantages for the state are several. It is relatively easy to start homes when proprietors assume a major responsibility for the development of the home, and this decentralized community-based approach avoids bureaucratic problems in operation since each home sets its own style.

Disadvantages of the model are in assuring continuing quality of the homes. When proprietors have a major role in setting the style, it is more difficult to raise the quality when needed. This problem is further compounded since in the Wisconsin system, the State Bureau of Mental Retardation (BMR) and the Wisconsin Colonies (state institutions) share the responsibility for supervision of the community homes in a manner that is not clearly defined. While the BMR sets standards and guidelines for the homes (with the invaluable assistance of the State Association for Retarded Citizens), locates proprietors, does some coordinating of placements, and revises fiscal formulae, the direct supervision of the homes is left to the Colonies. The Colonies are in turn limited in effect because the role of their staff is undefined: it is not clear who has the ultimate supervisory responsibility. Also, it appears that the only tangible link in the Community Living Systems network is provided by the Colonies' supervision of the homes. Nonetheless, the combination of the Colony's supervision of the Lori Knapp Home and the commitment and concern of its staff and proprietor have created a home of admirable quality.

G.

HAMILTON STREET RESIDENCE FOR CHILDREN

A group home using an intensive training program
for severely retarded children in the ENCOR system

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HAMILTON STREET RESIDENCE FOR CHILDREN

I. INTRODUCTION

Four years ago, shortly after the President's Committee on Mental Retardation identified normalization as the most important principle in developing services for mentally retarded people, a forward-looking parent group in Omaha, Nebraska began to put the principle into action. In the summer of 1970, the Greater Omaha Association for Retarded Children (GOARC) opened Hamilton Street Residence, a group home for six moderately and severely retarded children. The children were from both the state institution, and the community, and were all in need of intensive training. This was a courageous undertaking, particularly since professionals predicted that some of these children could not grow and develop.

Operation of the home was soon assumed by ENCOR, an agency created to take over direct services provided by GOARC. ENCOR has now become a five-county comprehensive service system for more than 1,000 persons, that includes these services: residential, vocational, developmental, recreational, counseling and guidance, transportation, and evaluation. These services have been developed as a cohesive network to provide the needs of any mentally retarded person, no matter how severe the handicap. During four years of operation ENCOR has demonstrated their commitment not only to the principle of normalization, but to non-segregated services, clusters of services in close proximity to one another, "spinning off" services to other community agencies, and to internal and external evaluation of their own services.

Gradually ENCOR has expanded the philosophy of Hamilton Street Children's Residence to include movement within their system of services. While during the first two years the home was considered a long-term training residence, it is now a short-term training residence which uses an intensive behavior modification program with relative success. The children, several of whom have severe behavior problems such as head banging, temper tantrums, childhood schizophrenia, biting, kicking, and scratching, are "programmed" to receive humanistic consequences for the behaviors. This intensive training seems to be working well since many of the aberrant behaviors have disappeared.

Movement upward through the system of alternative living situations is for children in the ENCOR system of services a primary goal that indicates the staff's underlying belief in the ability of retarded persons to continue to grow. Though the originators and staff of the home had this forward vision, they did not expect the outcome. In the beginning they

thought that some of the children would be able to enter public school programs within a year, but to their amazement three of the children were able to go to school within three months of moving to the home. One of the children from the institution who had been predicted to live for only five years is now ten years old and has learned to walk, talk, sing and attend school.

The success of the home has been due not only to the behavior modification program, but to the relationship of the staff to the children. Staff approach the children first as individuals, and secondly as children with special needs. Their overall application of the normalization principle is characterized by their juggling of attention to special needs with allowance of opportunities for freedom and exploration, while still maintaining a family atmosphere.

II. ENCOR

ENCOR, the Eastern Nebraska Community Office of Retardation, is a five-county agency in the Omaha area responsible for assuring that retarded people have a full range of services available in their community. Although established as recently as 1970, ENCOR, in just four years, has been able to develop a wide array of community services and is being used as a model of service for many other areas in the country.

In the late sixties a number of innovative and determined parents and professionals joined together to develop a community-based system of services. At the time there were virtually no community services for the mentally retarded in Nebraska, and Beatrice State Hospital, the state's only public institution, was both overcrowded and in poor condition. A 1968 plan prepared by a citizens' committee of parents and professionals proposed an extensive community-based system of services as the "solution" to the problems at Beatrice State Hospital. This was translated into legislation in 1968, creating six regions in the state where services would be provided as well as a state office of mental retardation to plan and coordinate.

Relationship to Greater Omaha Association for Retarded Citizens

Initially much of the program development in the Omaha area was carried out by the Greater Omaha Association for Retarded Children (GOARC). Since there was no one else to develop needed programs, they had established their own pilot, community-based programs although they saw their primary role as advocacy and monitoring of programs. They actively participated in the development of ENCOR, and gradually "spun-off" funded services to the new agency. ENCOR in turn has assumed the role of filling in the gaps in services provided, gradually turning programs over to community agencies. Now GOARC and ENCOR work together in a unique partnership: ENCOR develops and operates direct service programs while GOARC monitors programs to insure quality, and advocates for the rights of retarded persons.

ENCOR System of Services

By 1974 ENCOR was serving 1,127 retarded persons which includes 114 severely retarded individuals and eleven profoundly retarded persons. Two departments--Developmental and Vocational Services, and Family Resource Services--direct the following services (see Appendix A for ENCOR administrative structure):

1. Guidance--a central point of inquiry; child and adult counseling including development of Individual Program Plans for each person being served.

2. Transportation--bus or cab transportation to day programs and services; help in establishing car pools; training in using public transportation.

3. Specialized Services--speech, physical and occupational therapy, and medical and psychiatric consultation as well as psychological evaluation and testing.

4. Developmental Centers--six training centers serving approximately 100 children age 6 to 12 in motor, social and language development.

5. Vocational Services--five Industrial Training programs provide training for competitive employment. A program has also been developed providing work stations in industry for retarded people, and there is job placement and follow-up. Another program provides training for general work skills and attitude.

6. Coordinated Early Education Programs--forty children together with 8 staff have been placed in six normal preschool programs. The staff provide the extra assistance necessary to integrate the retarded children into the regular school program.

7. Recreational Services--ENCOR mainly works with existing recreation and leisure time programs to assist them in including retarded people.

In addition to these services, ENCOR has developed a number of different types of residences for retarded people that differ according to the age and ability of the residents. They are designed for children and adults alike as graduated steps in residential living that are increasingly more independent.

Residences for Children

Step 1: Specialized Residential Units:

Developmental Maximation Unit--residential care in a wing of a community hospital for 18 multi-handicapped children ordinarily placed in pediatric intensive care units in general hospitals or in infirmaries of institutions.

Step 2: Training Residences:

Children's Group Homes--three group homes with 6 children ranging in age from 3 to 15, operate much like a normal family. These are primarily intensive training homes.

Adolescent Group Home--one group home established for children in their late teens.

Step 3: Satellite Training Residences:

Alternative Living Units (ALU)--family homes in the community where one to three retarded children live together with a family. Training is continued under the supervision of houseparents of the group home the child moves from.

Other Children's Residences

Crisis Assistance Residence--this is a "respite" home where families may temporarily place their child while they deal with family problems such as an illness or death, or if they wish to take a vacation or otherwise need time away from their child. ENCOR has also arranged for private homes to take children on a short-term basis up to one month for similar reasons.

Residences for Adults

Step 1: Training Residences:

Adult Group Homes--eight adult homes ranging in size from 5 to 10 persons in a home-like atmosphere.

Step 2: Satellite Training Residences:

Alternative Living Units (ALU)--living arrangements of several kinds that are supervised by the houseparents of an adult training residence.

Step 3: Residential Apartments (Semi-independent living):

Co-Resident Apartments--apartments where two or three retarded adults and a non-retarded peer live together. The roommate/staff person provides friendly guidance in day-to-day matters such as shopping for groceries, paying the rent and so forth.

Counseling Apartments--apartments with one to three residents where a counselor stops by once a week to assist with household management and provide counseling for whatever other needs a resident has.

The final step for adults is movement to an independent living situation.

Philosophy of the Service System

The ENCOR system is permeated by the normalization principle. Indeed Wolfensberger, who wrote the book Normalization and developed the PASS Evaluation system to measure normalization (co-authored by Linda Glenn, present ENCOR Director), and Menolascino, one of the leaders in community-based normalized approaches; were among the group which created the changes in Nebraska.

In applying the normalization principle (that mentally retarded persons should have a life that is as normal as possible) ENCOR has developed these themes which are recurrent throughout the services of the system:

1. Services are integrated into services for the non-retarded. As much as possible, retarded people use existing community programs and services such as public schools, normal employment, public recreational facilities and so forth.

2. Services are clustered in supporting groups and dispersed throughout communities. A group home, developmental center, and a workshop are located within close proximity to support the services of the other. Services cannot be provided in a vacuum.

3. Services are continuous. Between agencies and within an agency programs are developed so that people can move as their ability improves and their needs change.

4. Services are "spun-off." ENCOR fills the service gaps in a further attempt to allow clients to use existing services in the community. It is the last resort for ENCOR to provide the service.

5. Services and programs are flexible and subject to continual change. Programs and philosophies are continually re-evaluated and personnel reorganized to meet the changing needs of a changing community. This constitutes a vision for the future.

6. Services are evaluated. Evaluation is done internally and externally to measure degree of normalization and program success. In training programs sensitive tools are used to measure client's slow progress, and to coordinate with other aspects of the client's program.

III. DEVELOPMENT OF HAMILTON STREET RESIDENCE FOR CHILDREN

GOARC

In 1970, before ENCOR was formed, the Greater Omaha Association for Retarded Citizens (GOARC) opened two group homes for children (known then as hostels). One of them was Hamilton Street Residence for Children.

GOARC had a long waiting list of moderately and severely retarded children from both the community and Beatrice State Hospital, who needed community-based programs, so they made children's homes their priority for the year's budget and plan. This action-oriented group of parents and professionals had made the decision not to wait for the two-year-old plan for a regional agency to develop services, but to proceed with their own plans. Once the new agency was formed, GOARC would hand the operation of the home over to it, though they would maintain influence in the future direction of the home by monitoring it to insure a good program.

GOARC planners thought that a developmental home (a foster home where one child was placed with a family) was the best kind of home to provide children with a nurturing environment. But they also knew that many of the children on their waiting list had severe behavior problems and would need special training, so they concentrated on plans for small group homes where houseparents and staff could be given training to work with six children in one home.

Obtaining a Building

GOARC's Residential Planning Committee began to search for a building that would make a good home for six children. It had to be designed to accommodate the space needs of the children, houseparents and houseparent assistants, and it had to be located in a neighborhood appropriate for the children with schools nearby. Even more problematic was finding a home that would meet group home licensing requirements that was also in an area that did not require re-zoning.

Finally, in the Spring of 1970, after looking at twenty or more homes, the committee located a tri-plex that seemed to meet these requirements, though it needed extensive renovation. The State Division of Child Welfare approved the home for a license if room uses were altered to create additional bedroom space. So, the committee, with a go-ahead from the GOARC Board of Directors, entered into a lease-option agreement. Since GOARC did not have enough money to buy the home themselves, an investor who was a realtor was obtained through one of the board members. The realtor purchased the home for them, and held a long-term (10 year) lease. The purchase price was set at $19,500 and they could buy it when they opted to. GOARC assumed the monthly costs of $460 which included taxes, insurance, and rent, paid to their realtor.

Renovation of the home included changes necessary to meet the terms of the fire inspection, as well as structural changes to make the living spaces adequate for the children. The fire marshall required that a smoke detection system connected to a remote control station be installed, and that the basement be made safe by replacing ceilings with heat-resistant ones as well as installing a solid core door between the first floor stairway and the basement. A later requirement was a fire escape addition to the back of the house. Structural changes consisted primarily of knocking out a wall between the two kitchens of the duplexes on the first floor to create one large kitchen that would also connect what would otherwise be separate apartments. (Costs for renovation remodeling amounted to nearly $10,000.)

The final obstacle to opening the home was a Public Safety Department requirement to obtain doctor's certification that the children were capable of self-preservation. A doctor on the GOARC Board of Directors agreed to certify the children, if the parents were willing to sign legal statements that he was not liable, and parents agreed to do so.

House Description

The house is a large brick home that looks much like any other house on the street. There is no tell-tale sign to call attention to it. It is located in the Walnut Hill addition of Omaha in a residential neighborhood and has a slowly changing complexion as more small businesses move into it. The street in front is a busy one, but fairly safe for the children since both the front and back yards are completely enclosed with cyclone fencing. The yards are large, and the backyard has a swing set. Two blocks away are a school and small shopping area, and beyond them is a neighborhood park

Inside the house, what had been a ground-level duplex, has been converted into a single dwelling, that consists of a kitchen, livingroom, diningroom, five bedrooms, and two baths. Four of the bedrooms are occupied by the children, three of which are private bedrooms for the three girls. A very large bedroom (which had been the livingroom of one apartment) is equipped with a bunkbed and a single bed to house three boys. The fourth bedroom is used by overnight staff or guests. The houseparents have their own private quarters downstairs in what once was a third apartment. Their space consists of a kitchen, livingroom, bedroom and bath. The houseparents and other staff feel that having this separate apartment downstairs is not ideal for interacting with the children, and is not normalizing since parents do not ordinarily have a separate apartment for themselves. To get to the houseparents' apartment from upstairs, you walk through a large recreation room where the children watch television and play checkers and other table games and draw at a large table.

The houseparents have decorated the home to be comfortable and pleasant with durable naugahyde furniture, and tables with wipeable formica tops. These are necessary since the children, as all children, are

relatively hard on the furniture. Children's bedrooms are decorated with juvenile fabrics and toys to be cheerful, though they lack the imprint of the child's personal expression which one would find in a normal child's bedroom. The two bathrooms are designed as normal bathrooms including inside locks for privacy.

What the house lacks most is adequate kitchen and dining space. These are rather long, narrow rooms that are often congested by being a thoroughfare for the large family of ten people (six children and three to four staff on duty). The dining table (actually two tables end to end) nearly fills the width of the diningroom, making it barely possible to pass through when everyone is seated for a meal. Although the residents and staff have learned to live with the tight quarters, the lack of space is a nuisance. This points up one of the problems of converting a family-sized home into a group home for a very large family.

The livingroom is another center of activity where the children especially enjoy the piano. Both the housemother and assistant housemother frequently play and the children sing along or just enjoy listening.

Selection of Residents

In Spring of 1970 final preparations were made to move into the home, and GOARC staff chose the children to live there. While ENCOR's present selection criteria is different from what it was then, GOARC simply chose half of the people from the community whose primary disability was mental retardation, and half from Beatrice State Hospital. (Current selection criteria are: first, people within the ENCOR system; second, people from Beatrice State Hospital; third, people from the community; and finally, people from out-of-county and out-of-state.)

GOARC staff chose four boys and two girls who were severely and moderately retarded for the new home. The children ranged in age from six to eight. The staff made it a point not to select only children who were likely to succeed. In fact, two of the children were from the "back wards" at the state hospital where they had been placed because of the severity of their conditions, and their extreme and bizarre behavior (head banging, compulsive self scratching, temper tantrums). Most of them were unable to feed or dress themselves, and several were not toilet trained. Some had no speech; several had severe emotional problems, and one had autistic behaviors. Although all of the children are now able to walk, two of them were unable to when they were brought to the home four years ago.

This selection supports GOARC's intent to explore within a community the adaptability of severely retarded children who would ordinarily have remained in an institution for life. Very few attempts had been made to do this, and yet they had faith in the potential success of their courageous experiment.

Staff Selection, Staffing Pattern, and Roles

In accordance with GOARC's adoption of the recently formulated normalization principle, they planned for a normal homelife for the children with houseparents who would be models of a normal family. A couple was sought who were sympathetic to the needs of the children, but who at the same time were kind and firm, mature and responsible, and in good health. An ad was placed in the local newspaper, and interviews conducted looking more for attitude and dedication than for academic and technical background. In addition to the houseparents, two full-time assistants who work mornings, evenings, and weekends, were hired. These are generally college students in psychology, social work, or a field related to the work in the home.

The job was more difficult than anyone had imagined. During the first year and a half, there was a high staff turnover involving four sets of houseparents. However, the present houseparents have been at Hamilton Residence for three years. They are a young couple in their mid-twenties with a young child of their own. The housemother had previously worked for the regional recreational center; the housefather had worked as a policeman. The housefather is finishing college, and the housemother has had one year of college in addition to several years of work experience. Both have received training in behavior modification techniques.

Since the home opened the number of household staff has been increased by three, so that now there are in addition to the houseparents, an assistant houseparent, and four residential assistants who all work full time (a total of 280 staff hours per week). Such a large staff is needed for a number of reasons. The original number of staff was too small to effectively meet the needs of six children with severe problems. This contributed to the earlier problems in keeping staff. Also, in addition to managing this home the staff is responsible for supervising satellite training residences. Finally, as ENCOR has gained experience, the training program within the home has been intensified, and the number of severely retarded children with complex disabilities in the home has been increased.

Initially, the primary responsibilities of the houseparents were management of the household and the children, teaching of living skills, supervision of supporting staff, and minimal record keeping. However, now that ENCOR has grown and changed its structure, administrative, training, and supervisory responsibilities have greatly increased. A recent houseparent job description has 21 administrative items which include meetings, conferences, and tours, as well as the development of training and job objectives for support staff, and the intensified training of residents. Tasks of supporting staff have also increased, in fact so much so that in order to insure that everything gets done, they periodically assign tasks in home staff meetings. A recent task assignment sheet listed responsibilities assumed in addition to working directly with the children. It read like this:

Assistant Houseparent:

Making contacts for Alternative Living Unit (ALU) Homes
Assisting ALU parents in locating services
Coordinating citizen advocates and volunteer staff

Residential Assistant:

Shopping for clothes
Supervison of housekeeping
Medication, Medical Sheets
Menu-planning
Grocery lists
Disseminating information from staff meetings
Procuring supplies

Residential Assistant:

Assess individual recreation needs (what needs stimulating?)
Collect recreation information around town
Checking stores for appropriate games
Maintaining petty cash account

Residential Assistant:

Contact ALU parents regarding behavior modification programs
Analyzes behavior modification programs for the children
Prepares forms for children's physicals
Attends teachers' meetings
Observes at Benson Developmental Center and Adolescent Education Program
Assists in training staff in Precision Teaching

Volunteers from several programs in the Omaha area frequently support the staff with donated hours. One source is the SWEAT Program, a Manpower Development program for high school students. Myers-Children's Rehabilitation Institute also places trainees in the home for fieldwork experience.

Qualifications for houseparent positions are dedication and five years of related experience (which can be as parents) and/or education. Though training for the jobs used to be minimal, all staff now receive a one-week orientation to the ENCOR system as well as continued in-service training and speical training by resource persons. The present houseparents worked for three months as relief houseparents to train for their positions.

Staff is first hired for a three month probationary period, and then evaluated at nine months and a year. Important items in their evaluation are the quality of their relationships with the children, and assessment of how they are applying their time as indicated by activity charts that show how much time they interact directly with residents as well as how much time they spend doing other tasks in the home.

Consequently, the role of houseparents identified by GOARC four years ago as "a mixture of parent and sympathetic boardinghouse landlord" has evolved to one of teacher-administrator-parent. Accordingly, job classifications and salaries have been adjusted so that houseparents each receive

$620 monthly for full-time work (or half the amount for part-time), and the relief houseparent receives $511 per month. Staff also assume the postures of friend and peer. The job calls continually on their patience, endurance, innovation, and willingness to give of themselves. Although it is a demanding job, the staff are deeply committed to the residents and like their work.

IV. PROGRAM

Philosophy of the Home

The normalization principle that permeates the ENCOR system penetrates nearly every aspect of Hamilton Street Children's Residence. The principle is emphasized by the administrative staff with what is probably unprecedented tenacity, due in part to the influence of ENCOR's director, Linda Glenn. She is co-author with Wolf Wolfensberger of the PASS evaluation system which scores the degree of application of normalization in community residences and programs down to the smallest detail.

The Hamilton staff has internalized this philosophy and applied it to such physical aspects of the home as the decor of the house, which is as normal as possible while still meeting licensing standards. The children's clothes and possessions are appropriate for their ages. Labeling is curtailed in referring to both the children and the house. For instance, referring to the home as Hamilton Children's Residence is frowned upon because normal homes do not have labels, as is referring to the actions of a child as "autistic" since the label itself places a negative value on deviance. These things are monitored and accomplished with relative ease, but what is a far more tenuous task is applying normalization to the "meat" of the home's program.

Staff attempt to approach the children first with concern about the "whole" individual, and secondly with attention to their special needs. This is no easy task when the children have as many special needs as these children do. To promote growth of the "whole" individual an attempt is made to create a family atmosphere. This is evidenced in the selection and roles of the staff, and in details such as prolonged evening meals and family meetings. Further, the family atmosphere is a relatively free one with rules limited to not leaving the neighborhood when playing outside, and a liberal bedtime of 9:00 p.m. on weekdays and 10:00 to 12:00 p.m. on weekends. The individualistic approach is also seen in the choices the children are given to express themselves: they are allowed to choose their own clothes, and they choose the chores they wish to do for the week (for which they are paid an allowance).

Where the approach becomes especially problematic for the staff is in attending to the special needs, while at the same time allowing for the rights and autonomy of the children. When the home first opened, the in-home training of the children was not so intense as to interfere with the home atmosphere: most formal training was done outside the home at a development center or at school. However, with experience, staff has discovered that the children seem to need constant reinforcement if they are to progress at any noticeable pace. Within the past two years, the

intensity of the training within the home has increased, and certainly not without its effects on the atmosphere of the home. Staff has responded with concrete attempts to balance the children's attended time with time for freedom and exploration. The staff now keep activity charts to determine the number of interactions they have with a child within a given time period. Staff's overall application of the normalization principle is characterized by this juggling of attention to special needs with allowance of opportunities for freedom and exploration, while still maintaining a family atmosphere. Considering the complexity of the task, their accomplishment is outstanding.

Daily Schedule

The daily schedule of the home is somewhat similar to that of any children's household, though complicated by the special needs of the children. The early morning rush to school requires that the staff give a goodly measure of assistance to the children in dressing and eating. Once the children have left for school in ENCOR or community transport vehicles, staff does household chores, errands, record keeping and innumerable small tasks. When the children return from school in mid-afternoon, they have free time to play until dinner, although the behavior modification programs are being used throughout the time. After the prolonged dinner which is prepared by staff, sometimes with aid from one of the children who helps as a "cook;" games, music, television, and baths are the activities of the evening.

Daytime Activity and School Programs

During school hours the children attend a program geared to their developmental and educational needs to obtain primary training. Three of the children attend TMR classrooms in the public schools, while two children attend Benson Developmental Center, and one attends an Adolescent Education Program. These programs attend to the development of motor skills, daily living skills, perceptual and sensory discrimination skills, speech and language development, and social skills at a level attainable by the child. The programs also assess and test the needs of the children, and provide the home staff with consultation on in-home programs to support the school training. One home staff member periodically attends the school programs to observe and note methods to be used in a consistent manner in the home. The developmental achievements of some of the children have been beyond the planners' expectations. Planners thought some of the previously institutionalized children would be able to attend school after a year in the home, but to everyone's amazement, two children were able to enter public school classrooms after only three months.

Recreation

Recreation is a difficult area for the home since half of the children are uninterested or unable to participate in organized activities or to occupy themselves. Only two of the children want to participate in games. For them there is frisbee, volleyball, croquet, and swimming. They also belong to community clubs and programs such as the YMCA, Bryant Community Center and South Omaha Boys Club. When these programs do not have sufficient staff to work with the children's special needs, an ENCOR staff member is sent along with the children to supervise their participation.

But for four of the children, their abilities and contact with the world are so limited that they are unable to play or make use of free time. Unless the staff is working with them, they have a tendency to revert to behaviors like rocking back and forth, or throwing temper tantrums, or picking at themselves. There is little communication among these children and hence little play activity between them. This area of their lives is of concern to the staff. Presently one staff member is giving recreation his special attention to see whether or not participation can be improved through the use of specially designed games or techniques. All of the children, however, go to neighborhood parks regularly, and staff try continually to involve the children in new activities.

Behavior Modification Program

Though specific training areas had been outlined for informal training since the home opened, for the first two years of operation they were not attended to with much structure or consistency, and some of the children were not progressing with as much change and movement as staff thought was possible. So, gradually a more structured behavior modification program has evolved.

The specific training areas outlined by Encor for in-home training are:

Self Management

1. Attending
2. Body motor skills
3. Hand motor skills
4. Toileting
5. Self feeding
6. Personal hygiene
7. Dressing
8. Clothes selection
9. Clothes maintenance
10. Grooming
11. Posture
12. Health care
13. Corrective devices

Communication

1. Non-verbal communication
2. Verbal communication
3. Verbal characteristics
4. Response to the social environment

Inter-personal Relations

1. Group participation
2. Care and sharing of property
3. Table manners
4. Interaction with others
5. Recreation

Environmental Structuring

1. Coping
2. Distinguishing properties of objects
3. Basic reading
4. Basic writing
5. Basic math
6. Time management
7. Currency management
8. Checking management
9. Housekeeping
10. Home management
11. Serving meals
12. Meal preparation

Environmental Access

1. Telephone usage
2. Media usage
3. Community orientation
4. Transportation
5. Eating away from home
6. Community activities

To set up the behavior modification program, staff had to agree upon an approach or approaches to use in managing the children. A program specialist worked with the staff, consulting and advising them. Together they reviewed child development and child management theories, and agreed upon what might be called a humanistic behavior modification approach. This kind of approach means that rather than punishing a child for an inappropriate behavior, an attempt is made to substitute a positive behavior for a negative one. For example, one child who did not know how to verbally express his anger, would frequently throw temper tantrums when angry. Staff would tell him he was angry, and ask him to say so, and the child would eventually learn verbal expression of the feeling and the inappropriate expression of anger would go away. When a punishment is resorted to, it takes the form of sending a child to a bedroom or limiting him in some way rather than physical punishment or spankings. Additionally, staff try to accentuate and praise positive behavior, and with children having a great many inappropriate behaviors this is sometimes most difficult.

The tool used for planning, recording, and charting the behavior modification "programs" (the specific plan for changing a selected behavior is called a "program") is Precision Teaching. This is a refined tool

to measure slow progress: it consists of four records: a behavioral objective sheet to set up long-term objectives and steps to meet them; a planning sheet to specifically outline the behavior plan--the behavior to be modified, and the reinforcement or consequence; a frequency record sheet that is a daily record of behaviors and reinforcements; a cycle chart that plots and graphs behaviors to represent a growth pattern. It is a recording method relatively easy to learn, and it was already being used in the developmental centers, so it is easier to coordinate behavior modification plans between home and daytime programs. Using such a tool has a number of benefits. It provides a consistent recording method for the staff, and at the same time gives them valuable feedback on the efficiency of a behavior program as it charts the progress of the child. To count behaviors and frequencies, staff use an innovative wrist counter, a leather bracelet with beads that can be pushed along a fine strip that works on the principle of the Chinese abacas. (Throughout ENCOR many staff members can be observed wearing these.)

Though the staff has been able to reach a fair amount of agreement about approaches to be used with the children, and though they have effective tools to use, behavior modification is still no easy task. It sometimes takes staff several hours of brainstorming to develop one "program" that is workable. This has been the case in developing "programs" for autistic behaviors. One child who apparently has a form of childhood schizophrenia and rocks back and forth, does fingerplaying, and self-abusive things like pulling out her hair and picking at her arms, used to come home from the developmental center, go straight to her room, and remain there withdrawn and alone for the afternoon. Staff worked together to develop some "programs" for her (staff must agree together on a "program" before they begin to use it) and decided that she should not be allowed to be alone very much, so they would constantly go and get her to include her in the household activities. Further, they designed a "program" called "intrusion time" where each staff member would take turns for five minutes a day relating to her by using her name repeatedly, contacting her physically (hugging or touching), just talking to her, or playing with her. The "instrusion time" was gradually increased to fifteen minutes and then twenty. After several weeks, her contact increased and she would even on occasion initiate contact herself. This was a victory that took tremendous patience on the part of the staff.

The staff feels that it is important not to "program" the children all of the time, they begin first to "program" behaviors that interfere with learning to help themselves eat, dress, or use the toilet. Head-banging, biting, scratching, kicking are among these. What they have discovered in this approach is that once the aberrant behavior has disappeared, underlying emotional problems become more apparent. Then staff must aid the children in understanding their emotions by identifying the emotion and telling the children how it feels. "Hair grabbing is anger, and it hurts people." "Kicking is anger, and it hurts people."

The staff not only program the children, but they program themselves. They chart the number of interactions they have with a child within a given time period in order to determine whether or not a child is getting the amount and kind of attention he needs. Without this it is too easy for staff to attend to the inappropriate behaviors while neglecting to reinforce good behavior. For instance, for a child who had a great many inappropriate behaviors, including hairpulling, they would praise him at close intervals for a specific good behavior that endured for at least five minutes, and would ignore the hairpulling. This way the child had the experience of positive response, and was not then so apt to settle for negative attention. Staff feel that it is rarely just the child who is responsible for his behavior, but that the attitudes and attention of those around the child have a definite effect on his behavior. The program specialist feels that the most important element of success in modifying behavior is not the design of any single program, but the enthusiasm and involvement of the staff. "An optimistic staff will generate success by trying new approaches until they do succeed."*

Program Results

Though the beginnings of Hamilton Street Children's Residence were like most new programs, somewhat haphazard, and according to one parent "not a bed of roses," staff and administrators have in the past four years gained experience that they have applied in the creation of increasingly more refined methods of operating the home. The results of the program have, because of these efforts, or perhaps inspite of these efforts, been notable.

The program results are best described by the progress of the children who have all benefited from living in the home. The following vignettes demonstrate the changes in some of the children:

Murray

A ten year old boy, who we will call Murray, is the "miracle child" of the home. He is a small, thin little guy with longish blonde hair that helps to disguise his elongated, unusually shaped head. He came to the home from Beatrice State Hospital four years ago. Doctors had predicted that he would not live beyond five years old, and that in the meantime he would be totally non-functioning. Since he had not been expected to live, he had not been included in any programs at the institution, and just sat or laid in his bed staring at walls until he was nearly six years old.

*Thanks to Bill Doucette, program specialist, for use of his program materials in writing this section.

Now Murray can not only walk, but run and ride a tricycle, and he can talk quite well, often repeating what you say as if to capture its meaning. He is a lively child who goes to special education classes at the public school, and can read, and add and subtract. In fact, staff thinks he is being held back in the TMR classes.

By the time this is written he will have moved from Hamilton Street Residence, along with a little friend and foster brother, to an Alternative Living Unit--a "real" family home, supervised by his present houseparents.

Johnny

Murray's little friend, Johnny, is eleven years old, and has also lived at Hamilton Street Residence for four years. He is rather tall for his age, has a "little professor" appearance with a rounded, puffy face, and a slightly protruding tummy. He wears black-rimmed glasses, and has ash blond ear-length hair.

Johnny could say little but "buh" for the first year and a half he was in the home, now he attempts sentences, although he still speaks with some difficulty. He is very inquisitive, and interested in gadgets and the way things work--a typical boy of his age in this regard. When you attempt to show him how something works, he responds, "Ah, see," and quickly grabs for the object to operate it himself. (He was particularly interested in my tape recorder, plugging in the cords, setting up the mike, talking into it, hearing it play back, and then taking it all apart and putting it away in the case.) Sometimes he has to be directed to the appropriate behavior, (he took off his pants as well as his shirt when getting ready to wash his hair in the kitchen sink, and had to be told that he only needed to remove his shirt) but generally he responds quite well to instructions and is a pleasure to have around.

Johnny was not always this way. He was difficult to manage because he had frequent temper tantrums, and would hit and kick and become extremely stubborn. Now that behavior is virtually gone, and he can express his anger more directly. He can reason very well, while four years ago he seemed not to understand the simplest instructions. He also attends the TMR classes at the public school, and enjoys his social life there, although he still has some academic difficulties.

He has moved to an Alternative Living Unit along with Murray, and is happy with his friend and new family.

Parents' reactions also indicate good program results. Parents of the children at Hamilton Street Residence have been very involved with the home since its inception. Most of them were members of GOARC and

were involved in the planning for the residence. After waiting so long for an appropriate place for their children, they were very relieved when it finally opened. Several parents continue to visit the home weekly. They have some minor complaints about the home, particularly about the inadequacy of the house itself and about the first sets of houseparents. But generally they are very pleased and positive about the home, staff and their children's progress. Parents of two of the children expressed a good deal of pleasure with the fact that their children can now dress, feed, and toilet themselves with little or no aid. One parent felt that her child "had advanced tremendously, and that there is no comparison with what he was like before."

Staff also indicate a good program. Staff are evaluated annually after initial more frequent evaluations. Comments made about the staff on the recent PASS evaluation were: "Generally an outstanding staff, both philosophically and in their implementation of philosophies." Since the staff of a home have more influence than any other aspect of a home's program, an outstanding staff is usually an indication of a good program.

Finally, ENCOR's regular evaluations of their own programs speak well of the home. Hamilton Street Residence, like all residences, is evaluated by staff from outside the home to determine how normalized the program is, how comprehensive the services are, and what the implications are for the future of the home. In the recent PASS evaluation of the home, it scored 755 points out of a possible 1,000, a good score considering the detailed application of the tool and the special problems the home must handle within a "normal" setting. Precision Teaching measures the progress of the residents, and while this measurement indicates that progress in some areas could probably be faster, this might be explained by the fact that the use of the tool is relatively new in the home, and that the staff is continuing to learn how to use it with its best effects. Nonetheless, the progress of the children is substantiated by other means already discussed.

Alternative Living Units

Alternative Living Units (ALU) are a new idea in the ENCOR system. They are satellite residences of several kinds that are supervised by training residences. Staff of the group homes are responsible for establishing ALU's for their own residents, and they also recruit, train and supervise the ALU staff (home teachers). This is done with extra caring since the staff who create the new home situation already have a personal relationship with the residents.

The development of ALU's represent ENCOR's commitment to change and movement. According to Ed Skarnulis, Residential Services Director, while ENCOR used to look toward establishing more group homes, they have

come to realize that the continued development of group homes may be resulting in the substitution of smaller institutions for larger state institutions. He feels that the entire system of services was originally designed to prepare children to move back to their natural homes if possible; he states: "There is nothing normalizing about a child being removed from his home and placed in an agency residential component."

Consequently, rather than establishing many more group homes, their residential program thrust for the future is to provide parents with the supporting services necessary to keep their children in their own homes, whether those services be remodeling of the home, special equipment, community support services, or in-home aides. For those children who are already in residences within the ENCOR system, they will be prepared to move either back to their own homes, or to Alternative Living Units. Three of the children from Hamilton Street Residence have recently moved to ALU's that are family homes in the community and they seem to be getting along nicely.

V. ADMINISTRATION AND FUNDING

Administration

The administration of ENCOR is a complex multi-county system in which the county commissioners of each of five counties sit on a governing board. The Executive Director, Linda Glenn, answers to this board, and she in turn directs four departments or service components: Division of Central Administrative Services, Division of Developmental and Vocational Services, Division of Residential Services, and Division of Family Resource Services. The service components under each of these departments are listed in the chart of ENCOR's Administrative Structure, Appendix A (please refer). The Division of Residential Services has five Area Coordinators who are responsible for the overall supervision of the group homes. Hamilton Children's Residence is coordinated by Grant Loyd, area coordinator for the district where the home is located. A staff member(s) in turn supervises Alternative Living Units for children who formerly lived in the residence.

Funding

In 1972-73 ENCOR had an annual budget of $3,237,147, which derived revenue from county, federal, state, public, and miscellaneous sources as follows: County funds from five counties--$662,617; Federal Funds--Social Security, staffing grants, and other--$1,931,392; State funds--Office of Mental Retardation, Department of Vocational Rehabilitation, Developmental Disabilities Council--$3,161,805; Direct contributions from the public and other miscellaneous sources--$3,161,805. Of the total budget $342,957 was expended on residential services which have the least amount of federal support.

The budget for the 1974-75 fiscal year for the Hamilton Street Children's Residence is $73,596 (see Table 1) which includes the supervison of Alternative Living Units (ALU) at $6,500/yr. The largest expenditure, nearly 70 percent of the total budget, is for salaries of the residential staff (1 houseparent couple, and 4 residential assistants). Costs of leasing and maintaining the home, and of food are the other large expenses. The cost per resident per year is $10,849; $904 per resident per month, and $30 per resident per day. By comparison, the new ALU residences cost about $12 per resident per day.

Table 1

Hamilton Street Children's Residence
1974-75 Annual Operating Budget

Housing and Maintenance		
House lease	$3,788	
Renovation contracts	1,400	
Building Insurance	200	
Liability Insurance	75	
Maintenance and equipment	1,950	
Fire extinguisher contract	100	
Utilities and telephone	1,780	
Household supplies	400	
Bed linen (4 year replacement)	300	
		$ 9,993
Food		
Groceries and household supplies	$7,200	
School lunches	100	
		$ 7,300
Personnel		
Residential staff salaries		$45,535*
Miscellaneous		
Client clothing	$1,500	
Client education	750	
Tuition and training	400	
Films and dictation	50	
Books and subscriptions	50	
Expendable supplies and postage	45	
		$ 2,795
Transportation		
Children's transportation	$ 50**	
Staff mileage	800	
Staff travel (conferences, etc.)	350	
		$ 1,200
TOTAL		$66,823

$10,849 per resident per year
$ 904 per resident per month
$ 30 per resident per day

*$52,035 less supervision of Alternative Living Unit by residential assistant at $6,500. Includes fringe benefits (10%).

**Most transportation of residents paid by transportation department.

VI. OBSERVATIONS

The Hamilton Street Children's Residence demonstrated that severely retarded with complex behavior problems can grow and mature beyond expectations of parents, professionals, and staff, in a community-based residence. Many measures have been taken to create a good program and judging from the progress of the children in developing their abilities to help themselves, in changing their behavior, and in developing their social skills, one would have to agree that the home is a good one.

A significant factor in the quality of the home is the relationship of the staff to the residents. With children who are very difficult to work with, they have taken a unique approach in seeing them first as "whole" individuals in need of freedom for exploration, and secondly as children whose special needs have to be met with special techniques. In staff's use of the behavior modification program, they have even taken a humanistic approach, and use positive substitutes for inappropriate behaviors rather than the negative consequences used in other such programs. They also attempt to accentuate the strengths of the children, some of whom entered the home with very few positive behaviors to comment upon. They work together as a cohesive staff, spending several hours in staff meetings working out programs together, so to maintain their consistent approach among them. For some of the children programs require hours of discussion to formulate, and then it is not even certain that they will work. Staff has undertaken this with admirable enthusiasm and commitment considering that they are working with behavior problems such as autism about which the professionals know little.

While the behavior modification program has been introduced to the home to change its complexion from one of a long-term group home to one of a short-term intensive training home, as well as to aid the children in achieving more movement and progress, its effects on the home atmosphere have not gone unnoticed. The "programming" of both the children and the staff creates a pressured environment in which everyone is accountable for every minute of time. Though this may be necessary for the children, one wonders about its effects upon the staff, and in turn about the effects of the pressured staff on the children.

The home also demonstrates the role of a comprehensive service system in the operation of community residences. The advantages of a comprehensive system are several. First, such a system has the ability to procure funding that might not ordinarily be available to a smaller organization, and they can at the same time provide residential services that are more cost beneficial as costs are spread over a number of residences. Secondly, the system can more easily provide within itself coordination of a program plan for an individual that might encompass the training program, and out-of-home training programs covering the same skills or material. With moderately and

severely retarded individuals this coordination and continual reinforcement of training is of prime necessity if the individual is to grow to his fullest potential. Thirdly, a system can in its own provision of residential steps, be certain that upward movement is made available to a resident as his needs change, while it is unlikely that single service units can always provide for the broad needs of an individual even when they draw from community resources.

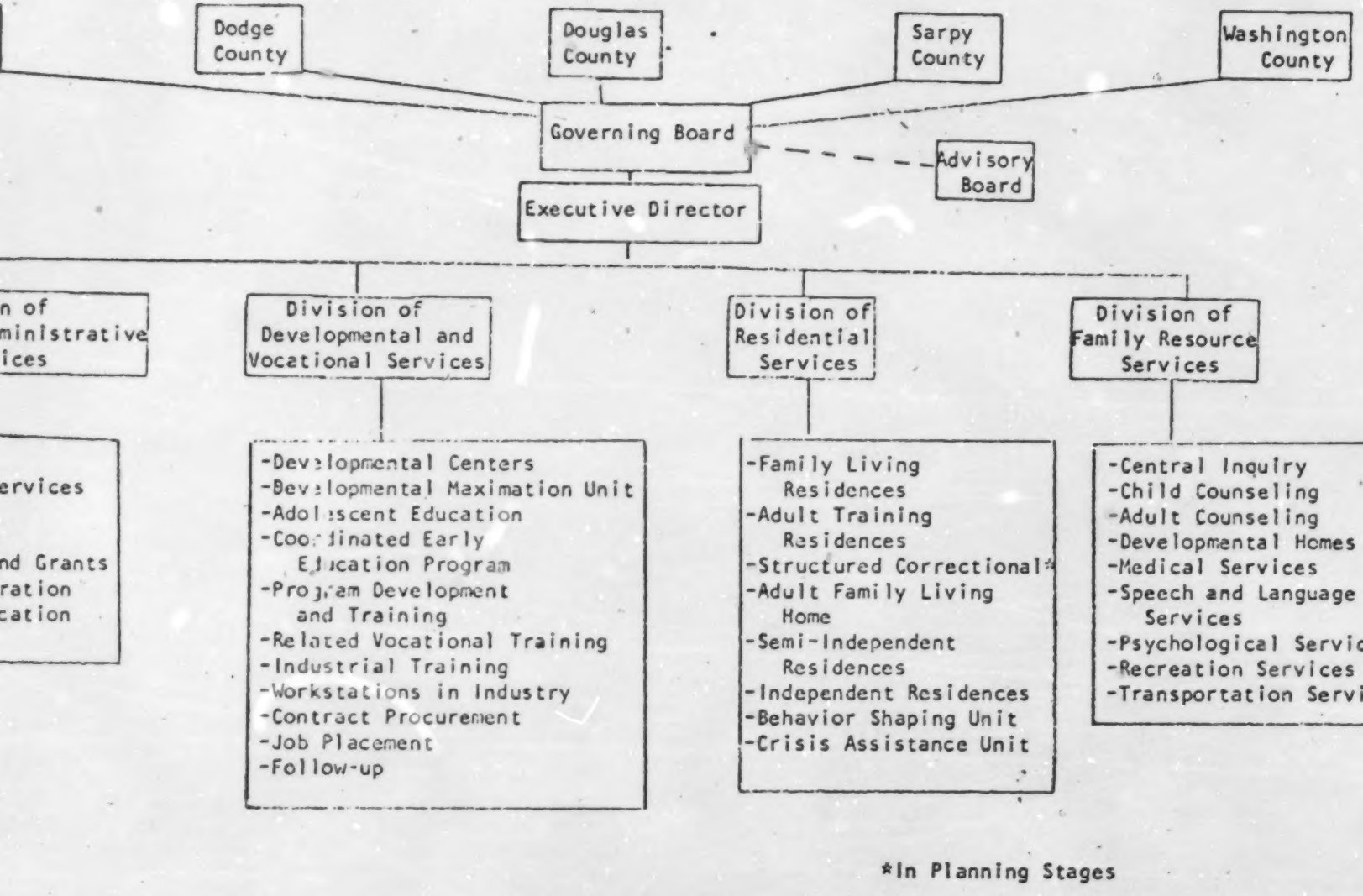
A disadvantage of such a large and comprehensive system might be in its administrative bureaucracy. The long link between administrative personnel, area coordinator, assistant area coordinator, houseparents, assistant houseparent, residential assistants, and home teachers of Alternative Living Units results in a communication channel that is timely, and often not adequate for the needs of the staff in implementing program changes, nor for their personal need for more immediate understanding of the workings of the system. The distant relationship with administration results in increased accountability, which has its adverse effects on staff morale.

Nonetheless, ENCOR has most certainly demonstrated a system successful in many respects. An ingredient in the success of the system is the commitment to change that is exhibited by the many changes in the system's structure and philosophy. This openness and availability to new programs and ideas gives the system its life to sustain itself. However, a danger may be in changing for the sake of change, or in movement for movement's sake, which would be at the expense of those served by the system. The recent move to open Alternative Living Units rather than additional group homes might be a change of this nature. The program appears to be premature for some of the residents who are being rapidly moved into it, with what appears to be little preparation of home teachers as well. Parents may feel that they will not have access to their children in someone else's home, while in the group home they do, and they may also have difficulty accepting that another normal family can manage their child while they cannot. They may also fear that non-professional staff may not be adequately trained to work with their children. These concerns are important to view with the eye of a parent. Whether or not the new program can circumvent these problems it is too early to tell.

APPENDIX A

Service Components of Present ENCOR Administrative Structure

Service Components of Present
ENCOR Administrative Structure



*In Planning Stages

OBSERVATIONS

OBSERVATIONS

Some Comparisons

These seven exemplary homes are strikingly diverse. True, they are all homes (or programs) for community living, but their styles, philosophy, size, sponsorship and characteristics of the residents are more different than they are similar. In this study, the diversity is expected since the selection of homes was made to include as many different kinds of homes as possible. But this diversity is also reported by others doing wide-spread surveys of community homes--the Planning Alternatives for Retarded Citizens project carried out at Harvard, and the study of group homes being conducted for HEW by the Rehabilitation Research and Training Center in Mental Retardation at the University of Oregon.

We believe this is a healthy diversity. The community-based approach is in its early formative years, and it is a time for experimentation. Furthermore, retarded people are very different in their abilities and their preferences. They have a right to be able to have available enough alternative residential settings so that their particular needs and desires can be met. Table 1 summarizes some of the similarities and differences among the homes studied.

However, beyond the [illegible]iceable diversity among the homes, there were also some common themes which occurred over and over again as we studied the homes. One theme is the close relationship between the motivating concept or philosophy of the home and its program.

The Relationship of Program Philosophy and Program Realities

The program philosophy or ideology of the homes is shaped and molded by a number of people: those who were the prime movers in establishing the homes, the houseparents or home operator, professionals who become involved in the home, and in some cases, parents. The philosophy is also influenced by the characteristics and personalities of the residents.

The program philosophy is like a hidden hand which influences even the smallest of details in the home. Who prepares the meals? Can residents be home alone? Should there be group or individual activities? The decisions on these and hundreds of other programmatic questions all seem to be influenced by the program philosophy which guides the home.

While most of the homes professed to be operating under the normalization principle, what this means in practice varied from home to home. The two areas of thinking which appear to have the greatest effect on the program philosophy are the concept of the retarded person and the goals of

Table 1

COMPARISON OF COMMUNITY RESIDENCES

NAME	SPONSOR	GOVERNING BOARD	NUMBER OF PEOPLE	EXEMPLARY FEATURES
1. Lupine House	Parents/ARC	Parents & professionals	6 mildly & moderately retarded women	Warm, home-like atmosphere; housework and skills training; parent involvement; outside administrator; housemother as counselor.
2. Community Living Project	Salvation Army	Mainly professional	26 men & women moderately & mildly retarded	Training of residents by counselors; emphasis on making decisions; community feeling; a transitional arrangemen to independent living.
3. Manchester Home	Mansfield State Training School	Institutional Board only	12 mildly & moderately retarded men	Started by an institution; back-up program by institution; leisure-time program; employment assistance by houseparents.
4. Hamilton Residence	ENCOR	ENCOR Board only	6 severely retarded children	Part of a system of services; use of behavior shaping program; normalization philosophy carried out in detail.
5. Lori Knapp Home	Parent originated	None	8 moderately to severely retarded boys & girls; 4 non-ambulatory	Warm, family atmosphere; extended family includes adult home; in-home program for severely retarded children; organized by a parent.
6. Cheyenne Village	Group of parents formed non-profit corporation	Interested citizens and parents	70 mild-moderately retarded men and women	A development and training program leading to independen living; reality approach stressing self responsibility; support of interested citizens.
7. The Hearth	Small group of committed religious individuals	Interested citizens and professionals	6-8 mildly & moderately retarded men and women	Residents and staff live together; spirituality; celebration; vision of retarded as people with intrinsic worth; strong sense of community.

the program. If the retarded person is perceived as being highly capable, then the program philosophy leans towards independence and self responsibility. However, if a person is perceived as being limited in his abilities, then the program philosophy tends to provide supports and sometimes restrictions in order to protect the person.

There were a variety of goals in the homes, both explicit and implicit. Most of the homes have more than one goal. Some of the goals include:

-- providing a more or less permanent residence

-- training residents so that they can live on their own

-- fostering a sense of human community

-- influencing society by providing a model

-- providing long-term protection to alleviate concerns of parents about the care of their children if they cannot take care of them

-- reducing public costs of caring for retarded people

-- decreasing the population in state institutions

-- altering behavior so that the retarded person can live in a less structured environment

-- providing an atmosphere for human growth and development

In the operation of the homes, these goals, together with the perceptions of the retarded people are a part of the construct which is the operating philosophy. The implication to others either operating homes or wishing to develop programs is that the operating philosophy is of great significance. It is well worth the time and effort it takes to carry out an extended dialog to shape, and indeed reshape, the philosophy.

In establishing the social environment of the home each establishment was faced with decisions about the balance between individual freedom and providing support. Individual freedom is intertwined with individual responsibility. Institutional living, and in some cases overprotective parents, often have created the conditions where individuals do not have to be responsible for themselves. By removing risk and uncertainty from the lives of retarded people, the conditions for dependency have been fostered. In the homes studied personal growth and development was greatest where residents were allowed the most freedom.

In most of the homes there is a firm concept of the ability of the individual to develop and improve in the skills needed for community living. The houseparents, by assuming that the residents can develop, make it possible for changes to occur. The phenomenon of the self-fulfilling prophecy was evident in case after case. Individuals who had long institutional

careers frequently have been able to obtain employment and live on their own in the community. A particularly useful manifestation of a developmental philosophy is having a system of homes with progressively less support. All of the homes studied, in one way or another, either had developed or were in the process of developing ways for residents to move to less sheltered residences. Cheyenne Village and ENCOR are good examples of a progression of homes leading to independent living. A system of residential settings, with progressively more independence, provides a person with specific goals, and a sense that he can and should move towards more independent status.

Because some of their abilities are limited, and they are painfully aware of these limitations, retarded people often have low self-esteem. A favorable social environment is one which helps the individual develop a sense of self worth. Staff can contribute to this sense if they develop a genuine interest in the residents and a liking for them. In every home studied we found this to be true to some degree. Frequently staff members will go fishing or otherwise spend time with residents on their time off. Almost all the staff reported that they enjoyed being with the residents and appreciated them as individuals.

The L'Arche vision sees the retarded as being particularly able to relate in certain areas of affect: loving, caring, feeling, responding to affection, and being spiritual. In a society which values the intellect and productivity, these attributes are often overlooked. However, these are areas of the culture where there is a new emergence. Perhaps as people come to adopt these new values the retarded people will come to be appreciated for their human qualities rather than the antipathy, fear and rejection they frequently now experience.

The Key Role of Staff

In setting the style and tone of a home what is of equal significance to program philosophy is the staff. Group homes are small social environments with comparatively few outside influences upon them. Because of staff's position of authority and their ability to direct the activities of the home, the staff plays a highly significant role in each of the settings studied. An unfortunate example is a home not described in this study which is precisely patterned after one of the seven homes described --similar setting, residents and program philosophy. However, the houseparent's personality and character are not the same, and according to a knowledgeable social worker who knows both homes, the similar home is "an abomination."

In two of the programs studied, Lupine House and Cheyenne Village, the "staff" included not only the houseparent or counselor in daily contact with the residents, but also the supervising administrators who had frequent interaction with the houseparent and counselors. In both programs

there has been staff turnover, but the style and quality of the home have remained consistent because of the influence of the supervising staff.

Although many of the staff involved in the homes had previous experience with retarded people, many did not. For a number of the houseparents and counselors their first experience with retarded people was when they started their job. What seems to be important in a staff person are the basic human qualities of awareness and sensitivity to others, genuine interest in relating to the residents as fellow human beings, and the energy and ability to put up with the frustrations and demands of such relationships. Vanier, in describing how he selects assistants, says he looks for a certain shine in a person's eyes when they talk about matters of life, and the tone of their skin.

Individualized Approach to Each Person

One of the noticeable features in the homes was the way each person was related to on an individual basis according to his/her particular abilities and needs. Time after time we noticed how special attention would be given to a resident--a rule modified, extra assistance to handle a situation, or a special firmness to help a person assume responsibility for him/herself.

It appears that such an individualized approach is somewhat easier when the number of persons in the home is few. There seems to be more room for flexibility (providing the houseparents are flexible). For example, a resident at the Community Living Project appealed to the Advisory Committee for an exception on the work rule and was allowed to pursue his avocation of antique collecting.

The Need for Community Programs and Services

For a community residence to be successful, there must be community programs and services in such areas as employment, education, leisure time, health, transportation and counseling. Naturally, in developing a community residence the focus of the organizers will be on residential services. However, it will soon be apparent that for the home to work, other community services are needed.

All of the programs were based on the assumption that the residents would have a daytime activity in the community--either competitive or sheltered employment, education, or attendance at an activity center. The implication is that those concerned with developing community residences must also become concerned with the full spectrum of community services available to retarded people.

One area that required special attention in all the homes was transportation. With a few notable exceptions, all of the residents were dependent on public or special transportation to get around in the community.

A variety of solutions were developed. In some cases sheltered workshops and other programs had special transportation for participants. Some of the homes owned their own cars, and in others residents learned to walk to work and other activities or to use public buses.

Sense of Community

Perhaps one of the long-lasting affects of the movement to create community residences of benefit to the general society will be demonstrating how people can live together in community. Because of their special circumstances, many retarded people will have to live together in group homes either for all or part of their life. But this is not necessarily a situation second best to living independently.

Many normal people are beginning to question the wisdom of living highly independent of others. The nuclear family, devoid of the support of relatives and friends, appears to be a social environment with a great amount of stress. Anthropologists like Margaret Mead point out that the isolated life of the nuclear family is a relatively new phenomenon. For most of history people have been part of a larger social network--the extended family, the village or the tribe. There seems to be a great yearning among a significant number of people for a sense of belonging, of being in community with other people. Many people are experimenting with different forms of community--communes, non-residential "family" networks and support groups.

In all of the programs studied the sense of community was very evident. In the Lori Knapp Home the extended family included the families of the staff and residents of the adult home. In the Community Living Project, the friendships and feeling of being part of a community, have developed spontaneously. There is a great deal of visiting between apartments and the weekly meeting of the residents is a time of friendly conviviality. How different the social environment is compared with similar apartment complexes where people have only a nodding acquaintance with their neighbors. The community which the Hearth is purposefully building includes not only retarded people living at their home, but also members of the community. When 14 members of the Hearth went on the pilgrimage to Canterbury, the group included in addition to the residents several assistants, people with cerebral palsy, who the members of the Hearth had reached out to, and people from the community who had come to be supporters and participants in the Hearth experience.

In the interest of meeting the normalization principle the goal of community residences frequently is seen as "independent living" meaning having an apartment or residence in the community with the "ties" to the group home or institution eventually severed. We wonder if such a goal misses an exciting opportunity of developing a social support network which the retarded person needs. Why not encourage former residents to

maintain their social ties with the group home by visiting, having dinner, and participating in social events? Or, why not encourage former residents to invite present residents to visit them and go to the movies together? Cheyenne Village makes it clear to its graduates that the Village stands ready to assist them whenever they need help in such vital areas as employment and personal counseling.

Learning about community may turn out to be but one of the significant lessons which can be learned from the community residence experiences. It is part of the larger lesson that people who happen to be retarded are a part of the human condition and they have something to contribute if we but have the eyes to see it.

Some Comments on Normalization

In recent years the field of mental retardation has been swept with a number of creative and helpful changes. Among these is the concept of normalization which states, "Utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible."* The dialog which this principle has created and its application in the everyday affairs of retarded people has undoubtedly created innumerable benefits. However, to remain vital, the ideology of normalization, like all ideologies, needs to be continually reassessed and expanded as further experience and insights accumulate. Throughout this study the concept and application of the normalization principle was of continuing concern since most of the homes had normalization as a part of their philosophy. The following comments are based on our observations and thinking about the homes.

One of the cherished ideals of this country has been that there was room for people who were different, both in their beliefs and in their practices. True, there have been many periods when individuals and groups were ostracized or even persecuted for their deviancy, but there has also been countervailing efforts both legal, moral and practical. The fifties and sixties were a period in which homogeneity was a prevailing mood expressed socially, by the extensive moral, legal and programmatic efforts to encourage racial integration. Recent social dialog, however, is in the direction of cultural pluralism. The inherent right, as well as the cultural benefit of being distinctively different are being emphasized. Thus, an American Indian or a Chicano can be proud of his origins and background, and society is coming to appreciate the distinctive differences of these subcultural groups which enrich the overall society.

In a time of cultural pluralism with so many different lifestyles among the 220 million people in America it is questionable whether there

*Wolfensberger, Wolf, The Principle of Normalization in Human Services, National Institute on Mental Retardation, Toronto, 1972, p. 28.

is a single cultural norm. The lifestyle of the middle-class suburbanite is one cultural norm, and certainly a prevalent one, but it is only one among many which is valued.

Is it not possible that the mentally retarded might be able to develop their own subculture which stems from their own abilities and interpretations of what it means to be human? The corrolates of normalization would have retarded people appear and act like everyone else. Yet one of the characteristics of subcultures are forms of address, appearance and behavior which help members identify with each other and to appear distinctive. By asking retarded people to be like people they are not, we may be denying them the satisfactions and support which they could derive from being with others who are similar to themselves. If, as a society we can come to appreciate each others' distinctive differences, could we come to see retarded people as having attributes which, while different, are of value?

The normalization principle contains within it an implied goal for the retarded person: that he act and behave as close to a "normal" person as possible. For a person of unimpaired intelligence this means, specifically, being able to read and write, handle rather complex problems intelligently, to have employment which pays well (generally the more pay the better) and so forth. For a great many retarded people, including those who are only mildly and moderately retarded, such goals are often unattainable. Is it fair to impose upon retarded people life goals which are not possible? Will not the effort to attain such goals only end in frustration and a pervading sense of inadequacy? One of the recurring themes which was reported to us at the homes was the inadequate self-image which retarded people have of themselves. Edgerton, in Cloak of Competence* describes so poignantly how the retarded people he studied attempted without success to appear normal:

> The ex-patients strive to cover themselves with a protective cloak of competence. To their own satisfaction they manage to locate such coverings, but the cloaks that they think protect them are in reality such tattered and transparent garments that they reveal their wearers in all their naked incompetence. In a sense, these retarded persons are like the emperor in the fairy tale who thought he was wearing the most elegant garments, but, in fact, was wearing nothing at all.

Perhaps the implicit message of normalization to retarded people is that they must be normal which means like other people.

More and more in the general culture, people are coming to the awareness that their life goals need to be derived from themselves rather than from "others." Frequently one hears of highly "successful" doctors,

*Edgerton, Robert B., The Cloak of Competence, University of California Press, Berkeley, 1967, p. 218.

businessmen, and engineers coming to the realization that they are achieving goals set for them by the society or their parents but which are not in harmony with their own desires or capabilities. Self-fulfillment is being seen as the goal which means realizing one's own potential. This is a life agenda coming from within rather than being imposed from the outside. Can we find ways to help retarded people become self-fulfilling people in which their own particular abilities, preferences and background are the guides?

If as a society we could do this, we would create a more humanized environment for the retarded. For we would recognize retarded people fully as fellow human beings with their own, distinctive characteristics and attributes. This approach would not negate the substantial benefits which have already been derived from the normalization principle. Rather, it would expand and fulfill that ideology's intent: to improve the life of retarded people.

I.

METHODOLOGY

METHODOLOGY

The method of detailed case studies used in this study is similar to observation/participation methods used in social anthropology in developing ethnographic reports. The primary source of information is field observations and interviews.

Selection

Selection of the homes presented several problems because no single person or agency has a sufficient overview of the 1,500 community residences in the United States to authoritatively single out the "best" homes. At the time of selection, two studies were underway which had undertaken mail surveys of homes in the United States (the University of Oregon study and the Harvard University study). Discussions with the staff of both projects were helpful in identifying different types of homes and obtaining suggestions on homes to inquire about.

From these inquiries and those of knowledgeable professionals in the field of mental retardation, a list of candidate homes was developed. Homes were further checked with other professionals in a manner much like the "reputational approach" used in political science studies of community power structures. The objective of the screening was to find homes which represented different models of care, different resident populations, different sponsorship, and a geographical distribution and which were considered "good" programs by competent and unbiased professionals.

Field Observation/Participation

All of the homes were visited during the winter of 1973 and spring and summer of 1975 to make on-site observations of the operations of the home. We were able to share in meals and activities and experience life in the home firsthand, and in most cases stayed several days and nights in the home. In some homes we also worked with residents and performed house managers' tasks. Interviews were conducted with residents, houseparents, social workers, parents, organizers of the home, state administrators and others who participate in the life of the home.

Relevant literature was reviewed and a detailed questionnaire was developed to assure that basic information about the home was obtained. However, the interviews were purposefully open-ended and the line of questioning was further developed by us during interviews to reveal what was unique and exemplary about each home. The basic areas of inquiry were: the origins of the home and early development, the program ideology and philosophy, the operational program, the relationship of staff and residents, the social environment of the home, the budget and

administration, and relationships with the community including participation in community services. Planning documents, budgets, newspaper clippings and articles about the home were used as secondary information sources.

Drafts of the case studies were reviewed by principals in each of the homes to check for accuracy of facts.

SELECTED BIBLIOGRAPHY

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The following are a selected list of books and pamphlets on the subject of community residences which would be useful to those currently operating a home or considering starting a home.

Baker, Bruce L., Seltzer, Gary B., and Seltzer, Marsha Mailick. As Close as Possible, Cambridge, Massachusetts: Read House, Harvard University, 1974.

A study of community residences for retarded adults prepared for the Massachusetts Developmental Disabilities Council which explains different models they found in a nationwide mail survey and studied through field investigations.

Clarke, Bill. Enough Room for Joy: Jean Vanier's L'Arche: A Message for Our Time, Toronto: McClelland and Stewart, Limited, 1974.

A description of L'Arche, the philosophy and way of life.

Edgerton, Robert B. The Cloak of Competence, Berkeley: University of California Press, 1967.

A perceptive study of a program of deinstitutionalized retarded adults.

Perske, Robert. New Directions for Parents of Persons Who are Retarded, Nashville: Abingdon Press, 1973.

A perceptive and sensitive book on forming new attitudes toward the retarded.

Residential Programming for Mentally Retarded Persons. National Association for Retarded Citizens, 1972.

Four pamphlets developed as part of a project, Parent Training in Residential Programming. They include, "The Process of Change," "A Developmental Model for Residential Services," "Developmental Programming in the Residential Facility," and "Prevailing Attitudes and Practices in the Field of Mental Retardation."

Respite Care for the Retarded. U.S. Department of Health, Education and Welfare, Washington, D. C., 1971.

Describes concepts of respite care and different models of service.

Silent Minority. Presidents Committee on Mental Retardation, Washington, D.C., 1973.

A book dealing with the life, liberty, and pursuit of happiness by retarded citizens.

Standards for Residential Facilities for the Mentally Retarded. Illinois, 1971.

Standards and evaluation criteria prepared by the Accreditation Council for Facilities for the Mentally Retarded in collaboration with the Joint Commission on Hospitals.

The Right to Choose. National Association for Retarded Citizens, Residential Services and Facilities Committee, 1973.

An 80 page pamphlet that describes in detail how to organize, operate and evaluate a home.

Wolfensberger, W. Normalization: The Principle of Normalization in Human Services, Toronto: National Institute on Mental Retardation, 1972.

Explains the normalization principle and its application, including methods of evaluation.

Wolfensberger, W. and Glenn, L. PASS: A Method for the Quantitative Evaluation of Human Services, Toronto: National Institute on Mental Retardation, 1973.